Understanding the lives of caregivers and evaluating a support programme for caregivers of children with disabilities: lessons learnt from Ghana

Maria Anne Zuurmond

Thesis submitted in accordance with the requirements for the degree of

Doctor of Philosophy. University of London
November 2021

Department of Global Health and Development

Faculty of Public Health Policy

LONDON SCHOOL OF HYGIENE & TROPICAL MEDICINE

No funding received for the PhD, but field work was supported by CBM International.

Research group affiliation: International Centre for Evidence in Disability

Declaration of my own work

‘I, Maria Zuurmond, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.’

Maria Zuurmond

Date: 26/10/21

Abstract

Background: Four fifths of the estimated 150 million children with disability in the world live in resource-poor settings where the role of the family is crucial in ensuring that these children survive and thrive. Despite their critical role, evidence is lacking on how to provide optimal support to these families.

Study aims: This study explores the lives of caregivers of children with cerebral palsy in Ghana, and the impact and underlying processes of a participatory training support programme.

Methods: A mixed methods study was conducted. This consisted of a pre-post survey conducted before (baseline) and after (endline) the training programme, with 75 caregivers enrolled from across eight districts in Ghana. A qualitative longitudinal study was conducted with 18 caregivers from four districts.

Key findings: Low levels of caregiver knowledge, pervasive stigma, and physical and emotional exhaustion, were all common themes at the outset. In terms of the programme impact, there were significant improvements in caregiver quality of life. Knowledge levels about their child's condition increased, and confidence levels increased in how to care for their child, including some aspects of improved care practices. Child outcomes were mixed, with some improvements in the child's health, but levels of malnutrition remained high.

The support group mechanism appeared to foster improved caregiver wellbeing and elements of caregiver empowerment through the acquisition of new skills, feeling valued by the group membership, and having a social support from this network. The latter included a realisation by caregivers that they were not alone, with a reduction in self-stigma, as well as having a safe space for problem-solving. Importantly, through sharing the experience of

other caregivers, this engendered a sense of hope that their child's life can improve. The complexity and non-linearity of the caregiver empowerment journey was illuminated. There were important gains in individual dimensions of power and the nascent emergence of collective power with other group members, but macro and structural issues limited possibilities for change.

The study illustrated the pervasiveness of disability-related stigma in the Ghana context for caregivers with a child with cerebral palsy. Stigma is multi-layered, and a range of factors interact with disability-related stigma, including gender and poverty. The evidence indicates that the caregivers in this study in Ghana can experience a form of disablism, which both impacts upon themselves, but also has repercussions on caregiving.

Conclusion: The findings illuminate the multi-faceted and interacting factors that directly and indirectly affect the lives of caregivers, and that a better understanding of the context of the caregiver-child dyad context is needed. A model of childhood disability requires that caregivers, and the gendered nature of caregiving, needs greater consideration, for a more transformative approach to childhood disability.

Contributors to the research presented in this thesis

As with any piece of research there are a variety of colleagues who contributed in different ways to different elements of the research, including my supervisors. The details of my contributions to each element of the study are detailed in Table 1. I have had a variety of supervisors; Sarah Bernays was my primary supervisor at the start (2016) and left on maternity leave and to take up a post at the University of Sydney but has remained in a key

advisory role. Martine Collumbien stepped in briefly and then Janet Seeley stayed with me throughout the journey and took on the mantle of lead supervisor. Tom Shakespeare joined the advisory team (2018) and then kindly agreed to step up to a supervisory role (2019). Sarah Polack joined in the final stages (2020).

Supervisors:

Primary supervisor: Professor Janet Seeley (JS), LSHTM

Co-supervisor/Advisor: Professor Tom Shakespeare (TS), LSHTM

Co-Supervisor: Professor Sarah Polack (SP), LSHTM

Advisor/Supervisor: Dr Sarah Bernays (SB), University of Sydney and LSHTM, and Martine Collumbien (LSHTM).

Upgrade Examiners: Professor Clare Gilbert, Dr Mary Wickenden

International advisory team for Ghana research: Dr Norgrove Penny, Dr Mel Adams, Dr Marko Kerac, and Dr Cally J. Tann

National Advisory team for Ghana research: Maxwell Akandem, Dr Eben Badoe, Jedidia Abanga, Hannah Awadzi.

Project team in Ghana: Dr Gifty Gyamah Nyante (GN), Marjolein Baltussen (MB), Sandra Carsamer (SC), Dr David O'Banion (DOB)

Administrative support: Jyoti Shah and Anthony Climpson-Stewart

Thank you to CBM International who funded the Ghana field work and development of the training programme.

In the table below I (MZ) particularly detail my roles within the various components of the research which are submitted for this thesis. Within each of the published papers additional detail is provided on the roles of co-authors.

☐ Please note that all photos displayed in this thesis were taken with written consent as part of the ethics process.

Table 1: List of contributions to each element of the study in this thesis

Activity	PhD student role (MZ)
Overall research project: Understanding the lives of caregivers and evaluating a support programme for caregivers of children with disabilities: lessons learnt from Ghana.	Principal investigator (MZ). Led on protocol development, overall conceptualisation & application for funding to CBM International.
Development of the parent training manual which is used in the thesis.	This development phase was conducted in Bangladesh in 2012-2013. My role (MZ) was lead researcher in this action research process. Additional papers on this stage provided in Appendix 1.
Overall research design for this Ghana research.	MZ led with input from advisory groups and supervisors.
Qualitative research component design & development of topic guides.	MZ led with input from advisory group and supervisors.
Qualitative research component field work.	MZ conducted interviews in three sites with support from GN at one site.
Qualitative research analysis.	MZ imported all transcripts into NVivo 10 and led on development of coding framework and analysis, with regular discussion with GN on key themes and with supervisors.
Quantitative survey baseline and endline.	MZ led on questionnaire development identification of quantitative tools with input from SP and advisory group. Data collection in the field led by DOB and SC, with remote supervision at a distance from MZ.
Quantitative survey - statistical analysis.	Sarah Polack led on all the statistical analysis for the baseline and endline survey data.
Papers 1-4 in thesis.	MZ was lead author on writing all manuscripts for publication submitted in this thesis. Each of the published papers have full list of authorship and roles.
Additional papers in Appendix 1.	MZ was the last author in two additional papers for Ghana. MZ was first author for two papers from Bangladesh which informed the development of the parent training programme.

Contents

DECLARATION OF MY OWN WORK II

ABSTRACT III

CONTRIBUTORS TO THE RESEARCH PRESENTED IN THIS THESIS IV

CONTENTS ..... **VIII**

LIST OF ABBREVIATIONS ..... **XIV**

CHAPTER ONE INTRODUCTION **1**

DISABILITY CONCEPTS AND MODELS 2

CHILDHOOD DISABILITY AND DEVELOPMENTAL DISABILITIES 7

CHILDREN WITH DISABILITIES 'LEFT BEHIND' 10

CAREGIVERS OF CHILDREN WITH DISABILITIES 11

GUIDING INTERNATIONAL FRAMEWORKS FOR WORKING WITH CHILDREN WITH DISABILITIES AND THEIR FAMILIES 13

HOME AND COMMUNITY-BASED CARE AND SUPPORT 14

THESIS AIMS AND OBJECTIVES 17

CHAPTER TWO A LITERATURE REVIEW: CAREGIVER EXPERIENCES AND THE IMPACT OF PARENTING PROGRAMMES **19**

OVERVIEW 19

INTRODUCTION 20

METHODS 20

RESULTS: UNDERSTANDING THE CAREGIVER EXPERIENCE 25

RESULTS - EVIDENCE ON THE IMPACT OF PARENTING PROGRAMMES 51

LIMITATIONS 62

CONCLUSION 62

CHAPTER THREE DETAILS OF THE PARENT TRAINING PROGRAMME **66**

OVERVIEW 66

THE DEVELOPMENT PROCESS FOR THE PARENT TRAINING PROGRAMME 67
DESCRIPTION OF THE OVERALL PROGRAMME 69
A DESCRIPTION OF THE PROGRAMME MODULES 70
THE UNDERPINNING APPROACH OF THE PROGRAMME 72
ADAPTING THE TRAINING TO THE GHANAIAN CONTEXT 73
CHAPTER FOUR METHODOLOGY 75
OVERALL STUDY DESIGN 76
THEORY OF CHANGE 77
RESEARCH PARADIGM 83
QUALITATIVE RESEARCH DESIGN 85
REFLEXIVITY AND MY ROLE 86
ETHICS 89
PROJECT LOCATION 90
DATA COLLECTION AND TOOLS 95
QUALITATIVE LONGITUDINAL RESEARCH COMPONENT 103
CHAPTER FIVE (PAPER 1) EVALUATING THE IMPACT OF A COMMUNITY-BASED PARENT TRAINING PROGRAMME FOR CHILDREN WITH CEREBRAL PALSY IN GHANA 109
CHAPTER SIX: LEARNING FROM THE LADDER OF LIFE TOOL 130
BACKGROUND 131
METHODS 136
RESULTS 141
DISCUSSION 149
CONCLUSION 155
CHAPTER SEVEN UNDERSTANDING THE IMPACT ON THE WELLBEING OF CAREGIVERS (PAPER 2) 156
CHAPTER EIGHT: ILLUMINATING THE ROLE OF CAREGIVER EMPOWERMENT (PAPER 3) 169
CHAPTER NINE EXPLORING CAREGIVER EXPERIENCES OF STIGMA IN GHANA - THEY INSULT ME BECAUSE OF MY CHILD (PAPER 4) 182

CHAPTER TEN DISCUSSION, RECOMMENDATIONS AND CONCLUSIONS 209

REVIEWING THE EVIDENCE: THE LIVES OF CAREGIVERS AND THE IMPACT OF PARENTING PROGRAMMES 212

THE CAREGIVER TRAINING PROGRAMME, 'GETTING TO KNOW CEREBRAL PALSY' 213

METHODOLOGY 213

RESULTS 215

ILLUMINATING THE CAREGIVER EMPOWERMENT PROCESS 218

UNDERSTANDING THE ROLE OF STIGMA 220

LESSONS LEARNT 221

IMPLICATIONS OF THE RESEARCH FINDINGS 230

STRENGTHS AND LIMITATIONS OF THE STUDY 235

STRENGTHS 235

LIMITATIONS 236

SUMMARY OF RECOMMENDATIONS 238

CONCLUSION 241

APPENDICES - PART 1 244

APPENDIX 1: SEARCH TERMS 244

APPENDIX 2: FLOW CHART DETAILING THE REVIEW OF PAPERS FROM SSA 245

APPENDIX 3: PAPERS INCLUDED IN THE REVIEW OF CAREGIVER EXPERIENCE 246

APPENDIX 4: LSHTM ETHICAL APPROVAL 253

APPENDIX 5: GHANA ETHICAL APPROVAL 254

APPENDIX 6 PEDSQL™ FAMILY IMPACT MODULE 255

APPENDIX 7: PEDSQL™ FAMILY IMPACT VERSION: KUSAAL COGNITIVE FIELD-TESTING REPORT 258

APPENDIX 8: BASELINE SURVEY QUESTIONNAIRE 266

APPENDIX 9: ENDLINE SURVEY QUESTIONNAIRE 280

APPENDIX 10: QUALITATIVE INTERVIEW GUIDES: BASELINE, MID-TERM, ENDLINE 298

APPENDICES PART 2 SUPPLEMENTARY PAPERS 315

REFERENCES 369

List of Figures

Figure 1: ICF model of disability CYP version 5

Figure 2 Overview of modules 69

Figure 3 Flow chart showing the research process 77

Figure 4 Theory of Change 78

Figure 5 Map to show areas where the programme was implemented 91

Figure 6 Mother explaining community mapping to her group, photo taken by a group member 109

Figure 7 Image of ladder of life 136

Figure 8 Flow chart illustrating number of caregivers who were asked additional questions 138

Figure 9: Median changes in LoL-QoL score 142

Figure 10: Distribution of caregiver LoL-QoL score at baseline and endline 143

Figure 11: Distribution of child LoL-QoL scores at baseline and endline 143

Figure 12: search strategy for Medline 244

List of tables

Table 1: List of contributions to each element of the study in this thesis vii

Table 2 Inclusion and Exclusion criteria 24

Table 3 Summary of parenting intervention studies 52

Table 4: Overview of training modules 71

Table 5 Thematic coding of Ladder of Life with example quotes 140

Table 6 Median changes in LoL-QoL score 142

Table 7 Factors which can improve caregiver LoL-QoL at baseline and endline. 144

Table 8 Factors that contribute to a lowering on caregiver LoL-QoL 146

Table 9 Caregiver-reported factors that will contribute to improving child LoL-QoL 147

Table 10 Parent report factors which contribute to a lowering of child LoL-QoL.....148

List of photos

Photo 1 Parent support group at one of the eight sites 66

Photo 2 Training of facilitators workshop April 2015 75

Photo 3 Master Training Northern Ghana 94

Photo 4 Mother explaining community mapping to her support group 109

Photo 5 Photo of group facilitator collecting consent for the study at baseline 130

Photo 6 Grandmother providing consent during the first visit 156

Photo 7 Grandmother attending the facilitator training with her grandson 169

Photo 8 Mother and grandmother being interviewed at baseline line 182

Photo 9 Grandmother discussing one of the parent handouts 209

List of Abbreviations

CBID: Community Based Inclusive Development

CBR: Community Based Rehabilitation

CYP: Children and young people

DPO: Disabled People's Organisation

GTKCP: Getting to know cerebral palsy programme

ICF: International Classification of Functioning, Disability and Health

ILO: International labour organisations

LMIC: Low- and middle-income country

LSHTM: London School of Hygiene & Tropical Medicine

NGO: Non-governmental organisation

PedsQL™: Paediatric Quality of Life Inventory

QoL: Quality of life

SSA: Sub-Saharan Africa

SDGs: Sustainable Development Goals

UNCRC: United Nations Convention on the rights of the child

UNCRPD: United Nations Convention on the Rights of Persons with Disabilities

WHO: World Health Organization

Structure of thesis

The thesis for this PhD is presented in the 'research paper style' format, in accordance with the London School of Hygiene & Tropical Medicine research degree regulations. It includes several different but related journal articles that have been published in peer-reviewed journals.

Details of the publications, as well as acknowledgement of other contributors, are included in the 'Research Paper Cover Sheets'. This thesis also contains linking materials to provide information not covered in the research papers and to ensure this thesis reads as a coherent body of work.

- ☐ **Chapter one** provides an overview of the context for children with disabilities in low- and middle-income settings (LMICs), it defines cerebral palsy, the underpinning frameworks, and the rationale for family-focused programmes of care and support. It details the overall aims and objectives of the study.
- ☐ **Chapter two** details a scoping review of the literature on the impact of caregiving in LMICs.
- ☐ **Chapter three** briefly summarises the development of the parent training programme on which this study is based.
- ☐ **Chapter four** documents the methodology of the study in Ghana.
- ☐ **Chapter five (Published Paper 1)** describes the impact of the intervention on both the child and caregiver, from an analysis of the quantitative data from the study.
- ☐ **Chapter six** details the results from the testing of a quality of life (QoL) tool, the Ladder of Life–QoL (LoL-QoL). It explores what it adds to our understanding of caregiver reported QoL, as a result of their engagement in the programme.

- ☐ **Chapter seven (Published Paper 2)** explores the impact on the caregiver QoL, from an analysis of the qualitative longitudinal data.
- ☐ **Chapter eight (Published Paper 3)** illuminates the role of caregiver empowerment and their engagement in the programme.
- ☐ **Chapter nine (Published paper 4)** explores the role of stigma in the lives of caregivers and how this shaped their engagement with, and impact of, the programme.
- ☐ **Chapter ten** summarises the findings, discusses a model of the caregiver environment, examines implications from the study findings, recommendations, and a conclusion.
- ☐ **Appendices Part 1** includes additional documents related to the literature search, ethics, study questionnaires and topic guides, and a copy of the Mapi report for cognitive testing of the *PedsQL™* tool.
- ☐ **Appendices Part 2** includes additional papers from Ghana, and from the development of the caregiver training programme (in Bangladesh) which were not submitted for this thesis but provide contextual information.

Chapter One Introduction

Overview

In this chapter I provide an overview of the context for children with disabilities in low- and middle-income settings (LMICs), the underpinning frameworks, and the rationale for family-focused programmes of care and support. I introduce the overall aims and objectives of the study.

Disability concepts and models

This thesis is about understanding the lives of caregivers who look after children with disabilities, in order to understand how to improve care and support mechanisms. Although the focus is largely on the lives of the caregivers, I will provide a brief overview of conceptual understandings and models of 'disability', and of the conceptual approach adopted within this thesis. This will help position the caregiver and family within a broader disability framing.

The World Report on Disability captures the complexity of defining disability, stating that '*Disability is complex, dynamic, multidimensional, and contested.*' (World Health Organization and World Bank, 2011bp.3). Historically, within some religious traditions, disability might be seen as a punishment as a result of a sin committed, or alternatively a 'gift' from God as a test of one's faith (Retief and Letšosa, 2018). According to the charity model, pity is felt towards the person's perceived tragedy, and support is provided in order to alleviate their suffering (Retief and Letšosa, 2018). With advances in medicine in the 1800s, the 'medical model' emerged, whereby disability was described as failure in bodily functioning. The resultant focus was on deficiency, such as a 'deformed' limb, rather than seeing the person as a whole, or wider environmental factors. One consequence of this model is treating people with disabilities as problems to be solved, so they can then fit into society (Retief and Letšosa, 2018, Haegele and Hodge, 2016).

In the 1960s and 1970s, the social model of disability evolved, originally from the British disability movement (Barnes, 2012, Abberley, 1987). As a response to strong criticism of the

medical model, and in distinct contrast, the social model of disability shifted the focus from the individual, and any functional limitations, and instead argued that disability was a social construct, a consequence of oppression by society, which needs to be addressed through societal change, and political engagement to decrease environmental barriers, rather than individual rehabilitation. A clear distinction was made between the 'impairment' and the 'disability' which results from these societal barriers (Hughes and Paterson, 1997, Shakespeare and Watson, 2001).

One of the criticisms of the social model (or family of social models that evolved) is that it ignores the individual's experience of their bodily functions and individual needs, and overestimates what can be accomplished by changing the environment alone. Instead, arguably, the nature of the impairment also plays some role in contributing to disability, and thus there needs to be recognition of the value of mitigating, alleviating or curing an underlying medical condition (Shakespeare, 2013, Palmer and Harley, 2012, Shakespeare, 2012).

A disability model which aims to synthesise elements of the medical and social model is the International Classification of Functioning, Disability and Health (ICF, Figure 1) (World Health Organisation, 2001). The ICF offers a bio-psycho-social model of disability, whereby disability is not an attribute of the person but the result of an '*interaction*' of the health condition with environmental and personal factors. The model starts with the health condition (a disease or disorder) which then gives rise to impairments in bodily functions, activity limitations and participation restrictions, in interaction with contextual factors.

Activity is defined as '*the execution of a task or action by an individual'* and 'Participation' is defined as '*involvement in a life situation'* (World Health Organisation, 2001). Environmental factors include products and technology, the natural and built environment; support and relationships, attitudes, and services, systems, and policies. Personal factors can include self-esteem and motivation, which can influence how much a person participates in society. Notably, the ICF treats disability as a continuum, rather than categorizing people with disabilities as a separate group (World Health Organization and World Bank, 2011b) (See Figure 1).

Building on this model, there is an ICF-children and youth version (ICF-CY) (World Health Organisation, 2007a) which adopts the same bio-psycho-social model of disability, but the accompanying guidance is focused on infancy, childhood and adolescence. See Figure 1: ICF model of disability CYP version. The guidance for this version particularly emphasises that the role of the family is critical in influencing the functioning of the child:

> *'Development is a dynamic process by which the child moves progressively from dependency on others for all activities in infancy towards physical, social and psychological maturity and independence in adolescence**.** In this dynamic process, the child's functioning is dependent on continuous interactions with the family or other caregivers in a close, social environment. Therefore, the functioning of the child cannot be seen in isolation but rather in terms of the child in the context of the family system. This is an important consideration in making judgements about the child's functioning in life situations.* ***The influence of family interactions on the child's functioning is greater in this developmental phase than at any later point in an individual's lifespan****. Further, as these interactions frame the acquisition of various skills over the first two decades of life, the role of the physical and social environment is crucial.'[emphasis added] (World Health Organisation, 2007bp.xv)*

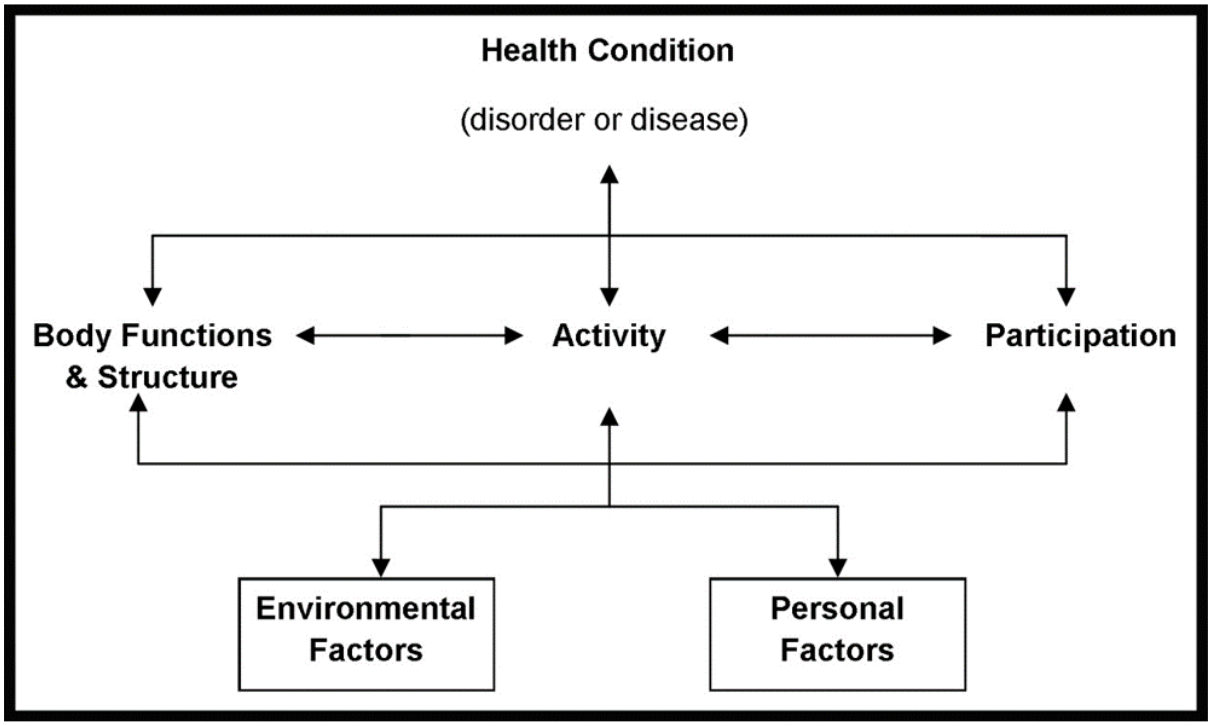


Figure 1: ICF model of disability CYP version

Given the focus of this thesis, I will briefly illustrate this model for a child with cerebral palsy. Cerebral palsy can impact on different bodily functions and structures (e.g. affecting oro-motor skills. This influences, and is influenced by, the ability to perform activities such ability to eat and to communicate. A consequence of this is that the child may have different levels of activities participation, for example in accessing being able to education, or being included in family social events. Contextual factors, a combination of environmental and personal, will also interact to shape the child's trajectory. Personal factors will include the particular background of an individual, such as gender, age, and levels of self-esteem. The environmental context covers factors such as the family environment, and broader factors such as inclusive policies and socio-cultural beliefs around disability. It would also include, amongst other factors, the availability, quality, and accessibility of services, such as health and rehabilitation services, and inclusive educational services. All these interactions are bi-

directional. Aligned with the ICF, in terms of the emphasis on the interaction between impairment and the environment, is the United Nations Convention on the Rights of Persons with Disabilities, which defines disability as a '*long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers, may hinder full and effective participation in society on an equal basis with others*.' (United Nations, 2006)

This ICF model is also not without its criticisms, largely from the proponents of the social model of disability. This includes the argument that the ICF still overly medicalises disability, implies impairment causes disability, is too apolitical, and lacks engagement with the disability movement (Barnes, 2012, Pfeiffer, 2000). A consequence is that policy is still too focused on prevention and/or treatment rather than societal changes needed (Tøssebro, 2004). Mitra and Shakespeare (2019) argue for the need for greater breadth and depth in the ICF model. Some of their criticisms include the need for the model to better reflect how health conditions can also directly influenced by contextual factors, that it is too narrow to assess life in terms of level of activity and participation, that there needs to be a place for individual agency, and to be able to account for how health conditions change over time.

Another critique of the various disability concepts and models is that they have largely been developed in the Global North, and there is a need to look at indigenous knowledge in relation to interpretations of disability (Mbazzi et al., 2020). In the East and Southern Africa context, the concept of 'Ubuntu' (`I am because we are') is found in several countries using slightly different terms, with implications for how social difference, including disability, is viewed (Mbazzi et al., 2020). Within this conceptualisation, disability is thus a social

construction which only happens when 'otherness' is seen as inhuman (Ngubane-Mokiwa, 2018). Maria Berghs (2017), for example, reflects that in the South Africa context, the concept of Ubuntu would result in more emphasis on the importance of the interrelatedness of humanity, and about respecting the '*diversity of humanness'*. She illustrates this with an example of a child with a disability in Ghana. Instead of a socio-cultural explanations for why the child or mother is to blame, the focus, using this Ubuntu framework, is to ask *'Why a community* or *institution or state is failing in its compassionate responsibilities towards upholding respect for human diversity, who is filling the gap and why, and what can be done' (Berghs, 2017p.6).*

Whilst acknowledging the strengths and weakness of the different disability models, for the purpose of this thesis, the ICF model of disability is adopted to frame the parenting programme. I detail how this conceptualisation of disability aligns with the Theory of Change and research design detailed in **Chapter four**. I then return to the ICF in the final chapter of this thesis, **Chapter ten,** and reflect on how this research can further enrich our understanding of the environment of the child, and in particular, the role of the caregiver. Whilst the African model of Ubuntu did not frame this research at the outset, I return to this model in my reflection on the research findings in the final chapter.

Childhood disability and developmental disabilities

Globally, one in 20 children aged less than 14 years is estimated to be living with a disability (UNICEF, 2013), and the vast majority (80%) of these children live in resource-poor settings (World Health Organization and World Bank, 2011b). It is also estimated that, globally, each

year an estimated 30 million neonates experience complications around the time of birth, which may have a life-long impact on health and development (Kohli-Lynch et al., 2019). Due to the complexities and inconsistencies in the assessment of childhood disability, global prevalence or incidence data for the range of childhood delays and disabilities is lacking (Collins et al., 2017). Challenges that contribute to both the lack of reliable data and difficulties in assessment include: the wide range of methodologies utilised; a lack of user-friendly and culturally-sensitive screening tools; tools that can over- or under-identify certain conditions; the lack of screening in most low-income settings; lack of clarity of what is defined as 'normal' in terms of early childhood development; as well as the role stigma can play in under-reporting (Palmer and Harley, 2012, Yousafzai et al., 2014, Olusanya et al., 2018, Collins et al., 2017).

Developmental disability is the most common cause of childhood disability. Estimates from 2016 suggested there were 52.9 million children under five with developmental disabilities, with an estimated 95% of whom live in LMICs (Olusanya et al., 2018). Data suggest increasing prevalence of children with developmental disabilities (between 1990-2016) in Sub-Saharan Africa (SSA). This may be due, in part, to better neonatal survival rates, especially for those born prematurely, and may also reflect improvements in data collection over this time (Olusanya et al., 2018).

Developmental disability is a very broad category that covers a heterogenous range of childhood conditions that can impact on a child's functioning over a lifetime (Smythe et al.,

2020b, Rosenbaum and Gorter, 2012). In this thesis, I adopt the definition of developmental disabilities from the Centers for Disease Control and Prevention (CDC):

> '*Developmental disabilities are a group of conditions due to an impairment in physical, learning, language, or behaviour areas. These conditions begin during the developmental period, may impact day-to-day functioning, and usually last throughout a person's lifetime.*' (Centers for Disease Control and Prevention)

Most commonly children with developmental disabilities have sensory impairments, cerebral palsy, epilepsy, attention deficit disorder, autism spectrum disorder, intellectual disability or developmental delays (Olusanya et al., 2018). Sometimes the term 'developmental disability' is used interchangeably with the concept of developmental delay. Whilst it is generally agreed that they are different concepts, terminology is often understood and used differently across settings and cultures (Wong, 2011). In this thesis, I commonly use the phrase 'children with disabilities' interchangeably with 'children with developmental disabilities'. This reflects the breadth of common conditions which fall under the category of 'developmental disability', and also takes into account the different way that terms are understood and used in different settings.

Cerebral palsy is the most common developmental disability with an estimated 2-2.5/1000 live births globally (Donald et al., 2015). A survey of childhood disability in Bangladesh showed that children with cerebral palsy account for the largest group of children with a moderate or severe physical disability, with a prevalence of 3.7/1000 children in Bangladesh (Murthy et al., 2014). The global estimates, however, are also likely to be an

underestimation. Specifically, in relation to estimates of cerebral palsy, Gladstone (2010) describes the particular challenges in resource-poor settings, whichinclude the lack of clarity over the definition of cerebral palsy, the different assessment tools used, as well as the low priority given to screening.

As well as having a motor disorder, children with cerebral palsy often have multiple co-morbidities, including visual, hearing, intellectual impairment, and epilepsy. The implication of this is that they generally require a multi-disciplinary approach to care and support, required over their lifetime (Colver et al., 2013a). This has repercussions for caregiving, as well as for any caregiving intervention. This will be explored further in this thesis in terms of the caregiver experience.

Children with disabilities 'left behind'

The Sustainable Development Goals (SDGs) emphasise the importance of *'leaving no one behind*' (United Nations, 2015) and persons with disabilities are identified as one of the vulnerable groups that are more likely to be 'left behind'. Children with disabilities are known to experience poorer health (Kuper et al., 2014, World Health Organization and World Bank, 2011b), as well as having diverse rehabilitation needs that are frequently not available in resource-poor settings (World Health Organization, 2013). These health and rehabilitation needs are often not met because there is a range of barriers in accessing services, or because these services simply do not exist (Bedford et al., 2013, Nesbitt et al., 2012, Bright et al., 2017). Similarly, children with disabilities are significantly less likely to attend school compared to their peers without disabilities and, even if they do attend, they

have poorer educational outcomes (Zuurmond et al., 2019, Kuper et al., 2014, World Health Organization and World Bank, 2011b). Children with disabilities are also at greater risk of violence, from the community, at school, and within the family (Banks et al., 2017a, Jones et al., 2012).

Caregivers of children with disabilities

The focus of this thesis is on the lives of caregivers and the evaluation of a caregiving programme for children with cerebral palsy, so it is worth explaining different definitions of caregivers. There are a variety of interchangeably used terms and definitions for caregivers. The CDC defines caregivers as those who '*provide care to people who need some degree of ongoing assistance with everyday tasks on a regular or daily basis. The recipients of care can live either in residential or institutional settings, range from children to older adults, and have chronic illnesses or disabling conditions. The term 'informal or unpaid' care is used to describe care provided by family or friends'.* (Centers for Disease Control and Prevention).

In some instances, the term '*family caregiver'* is also used to describe family members who take on primary caregiving and who '*without financial compensation, regularly assists a care recipient in carrying out one or more activitie*s.' These family caregivers '*often assume responsibility for a variety of services, which might traditionally have been provided by health service professionals, at least in higher-income settings'* (Shewchuk and Elliott, 2000p.555).

In other contexts, the term 'carer' is used to describe an informal or family caregiver:

> '*A carer is someone who provides unpaid care and support to a family member or friend who has a disability, illness, mental health condition or who needs extra help as they grow older. For some, taking on a caring role can be sudden: someone in your family has an accident or your child is born with a disability. For others, caring responsibilities can grow gradually over time. The amount and type of support that carers provide varies considerably. It can range from a few hours a week, to providing emotional support or personal care day and night.'* (CarersUK)

A common, well-established theme across the literature is that family members are generally the primary source of support for people with disabilities over their life course, particularly in low-resource settings with very limited health and rehabilitation services. They will inevitably have to provide a broad range of assistance (World Health Organization and World Bank, 2011b). Evidence demonstrates that in LMICs primary caregivers of children with disabilities are predominantly female relatives, most often mothers and grandmothers (McKenzie and McConkey, 2016, World Health Organization and World Bank, 2011b, Hartley et al., 2005).

As the focus of this research is on children with disabilities, there is sometimes an overlap between what might be considered 'parenting' and 'caregiving'. Some studies refer to the role of families, or parents, or mothers, or other family members, in the parenting and care and support of children with disabilities. Whilst arguably, everyone needs some form of care over their lifetime (Sevenhuijsen, 2003) and all young children need parenting, in this

literature we recognise that children with cerebral palsy and other children with developmental disabilities may have additional needs that can sometimes be multiple and complex.

Within this thesis the term 'caregiver' is used throughout and refers to a family member or guardian who cares for a child with a disability, without any financial compensation. The term 'primary caregiver' is used to denote the person who has the main caregiving role.

Guiding international frameworks for working with children with disabilities and their families

Given the focus on caregivers in this thesis, it is worth reflecting on the key global frameworks and guidance available for shaping the work with children with disabilities and their families. The UN Convention on the Rights of the Child (UNCRC) (United Nations, 1989) and the UN Convention of the Rights of Persons with Disabilities (UNCRPD) (United Nations, 2006) direct governments to be responsible for ensuring that all children enjoy their rights without discrimination, irrespective of any disability. Article 23 of the UNCRC specifically refers to children with a disability. It states that a child with a disability has a right to live a full and decent life and play an active part in the community. Importantly, governments should do all they can to support both the children and their families, and that families should be provided with *'early and comprehensive information, services and support'* (Article 23 UNCRC).

Another important framework is the WHO Community-Based Rehabilitation (CBR) guidelines, which inform the approach of community-based inclusive development (CBID). The CBR guidelines state the need to engage with families and the '*importance of empowering people with disabilities, their family members and communities… to ensure that everybody is able to access their rights and entitlements'* (WHO and UNESCO, 2010p.1). However, there is little detail provided in these guidelines about what '*empowerment*' means in practice for families. Similarly, the importance of agency is highlighted in the Global Strategy for Women's, Children's and Adolescents' Health (World Health Organization, 2016). This strategy demands a more 'transformative' agenda for maternal child and adolescent health, and the agency of families is seen as core to that approach. Women and children are considered the most '*powerful agents for improving their own health'* through developing their own individual potential to make informed decisions, combined with an active partnership with other stakeholders. This agency of the caregiver, in the context of the family and community, is explored in **Chapter eight** of this thesis**.** In the next section, I examine some of the reasons which point to the importance of developing family-focused programmes for LMIC settings.

Home and community-based care and support

The long-term impact of developmental disability on children's lives means that there is a need for a care and support model that starts early and can be sustainable over a lifetime. This supports the logic of engaging with families, especially when they are at the forefront of caregiving (Rosenbaum, 2011). In his substantial body of work in the field of children with cerebral palsy, Rosenbaum argues that there is a need to take a fresh approach to studies on childhood disability (Rosenbaum and Stewart, 2004, 2012, 2011). He emphasises the '*sea*

change' in our thinking and understanding about disability in recent years, and the need for programmes to move away from the medical model, and better reflect the factors within the ICF framework. This includes an emphasis on better understanding the role of family factors in the child's development.

The recent WHO Nurturing Care Framework (World Health Organization et al., 2018) also emphasises that strengthening families' and caregivers' capacity to support all young children's development is crucial to an enabling environment, alongside public policies and programmes. Whilst it is not a disability-specific framework, it recognises that factors such as disability, maternal depression, discrimination and living in extreme poverty can compound the challenges experienced. If these families are not supported, this will negatively affect young children's psychological and neurological development. Specifically, for early intervention programmes for children with disabilities, evidence highlights that working with families at an earlier stage can help them to adapt and improve responsive caregiving (Kohli-Lynch et al., 2019).

The critical need for family care and support also needs to be understood in the context of limited, or absence of, rehabilitative services in LMICs (World Health Organization and World Bank, 2011a). A Lancet commentary (Colver et al., 2013b) highlights the restricted access to health and rehabilitation services for the majority of children with cerebral palsy. An expert meeting on cerebral palsy in Africa similarly highlighted substantial gaps in rehabilitative services across 22 African countries (Donald et al., 2015). This frequently results in families providing the bulk of care for their child. Realistically, many families are

also unlikely to make the frequent visits required to such services, which is another strong argument that has been made for more home- and community-based intervention. Given the substantial global burden of developmental disabilities as detailed earlier, combined with the scarcity of services, families are likely to have to take on an even more significant role in many resource-poor settings. Specifically, in the Ghana context, the country in which the data collection for this thesis is based, medical rehabilitation services have been described as being minimal (Tinney et al., 2007, Donald et al., 2015), with only an estimated 150 registered physiotherapists for a population of 28.2 million, and the first cohort of nationally trained occupational therapists graduating only in 2017 (World Confederation of Physical Therapy).

Despite the agreed central importance of family, there is commonly little or no access to training and support for family members of children with disabilities (McConkey et al., 2000). Another criticism is that the research agenda has predominantly focused on prevalence studies, with little progress on evidence-based service development (Yousafzai et al., 2014). In the following chapter (**Chapter two**), I will review the evidence for parenting programmes, with a focus on SSA.

It is, therefore, not surprising that there have been calls for more research into community- and home-based programmes to improve care and support for children with disabilities in LMICs. These services should not only focus on the individual child but also need to meet the wider needs of the family, grounded on a good understanding of the family experience (Rosenbaum, 2011, Yousafzai et al., 2014, Beresford, 1994, Balasundaram, 1995, Hartley et

al., 2005, Raina et al., 2005, Olusanya et al., 2018). It is this gap in the literature that I aim to address in this thesis.

Given the need for family-focused programmes as outlined above, I was asked to lead on the development of a training programme for families of children with cerebral palsy in 2013, prior to this PhD. This training material was developed initially in Bangladesh, prior to this PhD, and a brief summary of the programme is detailed in **Chapter three**.

This PhD thesis aims to evaluate the impact of the programme in a different setting, and Ghana was selected as the site for this research. The choice of site was made in collaboration with the funding partner for the programme, CBM International.

Thesis aims and objectives

The overall aims of this thesis were twofold: to evaluate the impact of a caregiver training programme, and at the same time, to illuminate the lives of caregivers and their process of engagement in the programme. The rationale was to inform and strengthen approaches to a training programme for families of children with developmental disability.

Whilst the primary concern of the programme is the development and wellbeing of the children, it is clear from the ICF framework that the role of families is pivotal within the

child's life. This thesis is mainly focused on understanding the lives of the primary caregivers.

Study Objectives

- To assess the impact of a caregiver training programme upon the lives of children with cerebral palsy and their caregivers in Ghana (**Chapters five, six**)
- To explore the pathways of change for caregivers participating in the programme, with a focus on understanding the impact on caregiver wellbeing (**Chapter seven**)
- To illuminate the role of caregiver empowerment as the caregiver engaged with the programme (**Chapter eight**)
- To explore the role of stigma in the lives of caregivers, and how it shapes engagement in the programme (**Chapter nine**)

With these aims and objectives in mind, in the next chapter I review the literature on the impact of caregiving for children with disabilities in LMIC settings, with a focus on the SSA context. I also review the literature on the impact of parenting programmes, again with a focus on the SSA setting.

Chapter Two A literature review: caregiver experiences and the impact of parenting programmes

Overview

In this chapter, I review literature on the lives of caregivers of children with disabilities. The two main review objectives of the literature review are to explore: (1) the experiences of caregiving for a child with a disability, to better contextualise the parenting programme evaluated in this thesis, and (2) the evidence in relation to the impact of parenting programmes for children with a developmental disability. It is primarily focused on reviewing the evidence on caregiving experiences in SSA, whilst also reflecting upon a wider evidence base, largely drawn from other LMIC settings. It highlights the particular dearth of evidence on the effectiveness of parenting interventions, and gaps in the literature on the caregiver experience which this thesis aims to address.

Introduction

In this chapter, I review the literature on the lives of caregivers of children with disabilities, with a focus on the experience in SSA. The two main objectives of the literature review are to explore: (1) the experiences of caregiving for a child with a developmental disability, and (2) the evidence in relation to the impact of parenting programmes for children with a developmental disability.

Methods

The literature review is made up of two distinct components, conducted at different stages of the PhD study:

(1) In 2015, at the start of the Ghana project, I conducted an initial broad and light review of the caregiving literature, for children with disabilities in LMICs. Four databases were searched for studies that described the caregiving experience: PubMed, Embase, PsycINFO and Web of Science. Additional literature was also collated over the course of the study, through key informants and conducting additional strategic searches on specific topics of interest. Whilst the main focus was on understanding experiences in LMICs, I also drew on the literature from high-income settings for some topics, to better understand differences and/or gaps in the data.

(2) A more comprehensive updated literature review was conducted in May 2021, with a specific focus on caregivers of children with developmental disabilities in SSA. A comprehensive approach to identifying the relevant literature was undertaken in line with guidance for conducting scoping literature reviews (Peters et al., 2015, Grant and

Booth, 2009). The detailed methodology for this literature review component is further detailed below.

Search strategy for the review

Five databases were searched in May 2021 for the literature review on caregivers of children with developmental disabilities in SSA: CINAHL, Embase, Medline, PsycINFO, and Scopus. The choice of databases and the options for the different search terms were discussed with two LSHTM librarians (RB, JF). A broad search strategy was designed, and pilot tested, in order to identify studies relevant to both of the review objectives: exploring the caregiver experiences and caregiver/parent programmes.

The definitions of 'children with developmental disability' and of 'caregivers', used in this thesis, are detailed in **Chapter one** and they were adopted for the search strategy. I used a wide range of generic terms to capture 'developmental disability' to reflect how terminology is differently understood and utilised in relation to childhood developmental disability (see section on Childhood disability and developmental disabilities in **Chapter 1**). The key words used included a combination of umbrella terms for developmental disability: 'developmental disability, neurodevelopmental disability, intellectual disability/disorder, impairment, disorder, handicap, mental retardation, learning disorder'. Given the particular focus of this PhD, 'cerebral palsy' was also included as a search term, but other specific conditions, such as 'autism', were not included.

Child terms included 'child' or 'infant' as key words and MeSH (Medical subject headings) terms. 'Adolescent' was not used as a search term, as they are not the target age group of

the caregiver intervention explored in this thesis. Caregiver terms included the MeSH term for caregiver, and key words included a combination of 'carer, caring, caregiver, caretaker, expert parent, maternal/paternal, mother, father, family, families, parent(s)'. The final search strings and combinations varied depending on the database utilised, and an example is provided in Appendix 1: Search terms.

Screening for the literature review on SSA

Screening of papers involved several stages, drawing upon guidance for conducting scoping literature reviews as this was considered most relevant to the purpose of this literature review (Peters et al., 2015). A flow chart of the review process is provided in Appendix 2: Flow chart detailing the review of papers from SSA. In the first instance, the title and abstract were screened against the inclusion/exclusion criteria for each of the review objectives. Where several papers related to one study, they were included if they explored different aspects of the caregiver experience, or of the intervention. In the second phase of screening, full text papers were assessed for eligibility against the inclusion/exclusion criteria. Papers that I considered 'possible for inclusion' were reviewed by a second researcher (SP) and consensus was reached through discussion.

Inclusion/exclusion criteria

The full inclusion/exclusion criteria are detailed in Table 2. There is often tension between depth and breadth of literature reviews and decisions were taken for this review to enable meaningful engagement with, and synthesis of, literature in the context of this PhD thesis.

For the purpose of Objective 1, only qualitative and mixed methods studies were included. Pragmatically, considering the large number of studies, this was warranted to enable meaningful engagement with the literature identified. Further, this was considered appropriate given the context of this PhD, as the priority was to gain an in-depth understanding of caregiver lives which is afforded by qualitative data, to inform the caregiver training programme. The breadth of the term 'developmental disabilities' is broad, as already defined in **Chapter one** and I purposely wanted to include studies with children with wide-ranging conditions which fall into this category. However, to also make the review manageable, I elected to exclude studies that focused exclusively on children with autism, attention deficit hyperactivity disorder (ADHD), and epilepsy. Studies related to physical disability were only included where it was explicit that the sample included children with cerebral palsy. Studies that focused on HIV-related disability or childhood chronic conditions were excluded.

For Objective 2, where literature is more limited, all study designs and methods of data collection (quantitative, qualitative, and mixed methods) were included. However, papers which only described the process of development of the intervention, without any pilot testing with caregivers, were excluded.

Table 2 Inclusion and Exclusion criteria

Inclusion Criteria	Exclusion Criteria
Objective 1: Caregiver experience	
Caregivers of a child with developmental disability. This included children with intellectual disability, cerebral palsy, with sensory impairments.	Child has a chronic sickness/illness and children with an HIV-related disability. Studies exclusively focused on children with epilepsy & children on the autism spectrum.
The primary focus must be on the caregiver experience and/or their needs in relation to caregiving. Data related to this must be included in results.	If the study's primary focus was on parental experience with school and education services, and/or narrowly focused on their engagement with health services only.
Publications can be qualitative or mixed methods.	The focus of the paper is only on assessment of the child outcomes and not exploring aspects of the caregiver experience.
Focus on SSA.	Dissertations, posters.
Empirical data and literature reviews.	My own studies from this thesis were excluded.
Peer-reviewed publications from 2000 to May 2021.	
English only.	
Objective 2: Impact of parenting programmes	
The primary focus is caregivers of children with developmental disabilities. Programmes targeted at *only* groups of children with epilepsy or autism excluded.	Where main target of the programme is not caregivers i.e. health professional or directly to child only.
Programmes can be run as groups and/or individually focused.	Peer reviewed journal articles.
All types of methodology & including both process and outcome papers.	Protocols.
CBR-type interventions, but only where there is an explicit parent component which is separately described.	Where the intervention is only focused on parental engagement with schools.
The 'programme' should provide some formal input, which needs to be described by the paper.	Not a paper describing 'self-help groups' only, with no formal input.
At a minimum the programme needed to have been piloted.	The paper describes the development process of the intervention only, and there is no piloting.
Empirical studies or literature reviews.	
From 2000 to May 2021.	
English only.	

Data extraction and review

Data from the papers from SSA were extracted into a table that is provided in Appendix 3: Papers included in the review of caregiver experience. Data extracted included study aims, sample size, brief summary of study design, and methods. A simple thematic analysis of the qualitative data was conducted to identify key main themes described. For the review of parenting programmes, data extracted also included details of sample size, study design, methods, and summary of results. This is detailed in Table 3 Summary of parenting intervention studies. Formal quality assessment of the studies was not conducted; however, I do reflect on some of the strengths and limitations of the literature in the results section.

It is beyond the scope of this review to provide a detailed exploration of every thematic issue, given the range of experiences relevant to caregivers. The structured search enabled key relevant literature relating to caregiver experience to be identified from SSA and this was supplemented by other literature identified throughout the PhD. Some of these themes, notably stigma and empowerment, are then explored in greater depth in **Chapters eight** and **nine**.

Results: understanding the caregiver experience

In presenting the results of this literature review, I firstly provide an overview of the key thematic issues in the identified studies from SSA and illustrate these with specific details from one or two studies. These latter studies are selected because they illustrate an experience particularly well, or to draw out contrasting results and/or to illustrate

similarities across countries or contexts. Finally, I draw on evidence from a wider body of literature, mainly from LMICs.

Overview

In total, 35 papers were included in the literature review on the caregiver experience in SSA. This included one literature review, and 34 primary studies. Of the 34 studies, nine studies focused specifically on caregivers of children with cerebral palsy, whilst the other studies examined more broadly children with developmental disabilities, often with mixed groups of children with different types of conditions. The studies were conducted in 11 countries: Botswana (1), Democratic Republic of the Congo [DRC] (1) Ethiopia (2), Ghana (6), Kenya (5), Malawi (3), South Africa (8), Tanzania (2), Uganda (3), Zambia (1), Zimbabwe (2).

A large proportion (25/35) of studies were published from 2016 onwards. Most commonly, the study design was cross-sectional, with semi-structured interviews (SSIs), in-depth interviews (IDISs), and/or focus group discussions (FGDs). Three studies used a case study and/or ethnographic design following a smaller number of families over a period of time. Six studies employed more participatory approaches, such as photo-elicitation/PhotoVoice, or participatory workshops. The review publication is a narrative synthesis of caregiver experiences of raising a child with intellectual disabilities in Africa (Mkabile et al., 2021). Six of the nine publications included in this review by Mkabile were also captured in the current literature review. Whilst I separate out the findings from the review, there remains some duplication of data.

Twice the number of primary studies were conducted in urban settings (n=21), in comparison to rural settings (n=9), with a smaller number looking at both settings (n=3). In one study the setting was unclear. Most commonly the empirical studies recruited participants through inpatient/outpatient clinics, and /or families who used a specific educational or NGO service (n=25).

In 22 studies, the study participants were mainly female caregivers, predominantly mothers, typically with only two or three fathers represented in each study. Of these, eight studies included only women. A further seven studies did not provide data on the gender of the caregiver, although notably they did provide details on the gender of the child.

Knowledge, understanding and beliefs about the child's condition

The majority of studies that reported on caregiver beliefs and understanding and consistently illustrated low levels of knowledge or confusion, amongst caregivers and family members, about their child's condition (Den Besten et al., 2016, Tigere and Makhubele, 2019, Sandy et al., 2013b, Patel et al., 2017), including limited understanding about what their child may be capable of, combined with a lack of understanding about how to care for their child (Gladstone et al., 2017). Most commonly caregivers hold pluralistic and concurrent views on the causes of the disability, which include both a combination of bio-medical and traditional beliefs. Whilst there is variation in the detail of the traditional beliefs, there is also considerable similarity across countries and contexts, with disability often considered as a misfortune as a result of previous actions of an individual or the family, the result of witchcraft, 'God's will', and/or the intervention of ancestors (Hartley et

al., 2005, Namazzi et al., 2020, Tilahun et al., 2016, Muderedzi et al., 2017). Previous actions which were commonly assigned to the cause of the disability included marital infidelity, or the consequence of rituals undertaken for the family to become rich. For example, this was illustrated in a study with 62 caregivers of children with cerebral palsy in Botswana, where one mother reflected, *'Because it's like in our tradition there is this myth that if a child is doing like this it means one of the parents has went outside of marriage and had sex with somebody else to make the child like that.'(Patel et al., 2017p.864)*

The studies identified by the formal search process, described above, focused on caregiver/parent studies. However, these beliefs are obviously shaped by broader contextual and cultural narratives about disability. In terms of the wider evidence based on beliefs and understanding related to disability, holding pluralistic views on the causes of disability is commonplace in many LMIC contexts (World Health Organization and World Bank, 2011b). A recent study in rural Kenya explored community perceptions of disability (Bunning et al., 2017) and how cultural beliefs shaped understanding and acceptance of disability. The narratives illustrated the sometimes overlapping categories of '*Oneself*', '*Otherness*', and '*Fate, nature, or the will of God*', using the framework proposed by Ingstad (1990). 'Oneself' indicates a responsibility for a wrong-doing which results in a disability; 'Otherness' attributes the disability to an external cause, such as evil spirits; and 'Fate, nature, or the will of God' as a third category. In the mix of the plurality of beliefs, the findings also illustrated understanding of biological causes. The authors reflect on the fluidity of the explanations, especially in the context of limited information and resources,

and that families are, understandably, likely to shift beliefs as they seek to make sense of, and improve, their child's situation.

As well as community beliefs, the review illustrates the common lack of access to, and information from, health professionals, often with little or no available care and support options from health services. For example, in a study conducted in Malawi, caregivers of children with visual impairment reported difficulties obtaining any advice from health professionals, with most caregivers reportedly not understanding that their child could be helped to develop (Gladstone et al., 2017). Even where diagnoses were provided, parents can still struggle to understand what that means in practice for how they care for and support their child (Pretorius and Steadman, 2018, Tigere and Makhubele, 2019). These issues are further discussed in the section below on access to health services.

This lack of information and low level of caregiver understanding can contribute to feelings of frustration, as well as concerns about the future (Hartley et al., 2005, Tigere and Makhubele, 2019, Patel et al., 2017). It can also be one of several contributing factors towards why caregivers continue searching for a cure for their child, from biomedical services and/or traditional healers. Other factors highlighted which can contribute to this constant search for a cure include the lack of, or limited, available biomedical treatment options. This is illustrated by a study in rural Ghana in which caregivers sought treatment from various traditional healers (Nyante and Carpenter, 2019). One caregiver explained "*I figured it could not be treated at the hospital and must be spiritual*'(Nyante and Carpenter, 2019p.818). A study by Gona et al (2011p.180) in Kenya described an '*obsession*' to find a

cure which can drive caregivers to move from healer to healer. They argue that this may also be understandable as a caregiver coping mechanism, providing a valuable second opinion, and offering hope for some kind of treatment. The review of caregiver experience for children with intellectual disability (Mkabile et al., 2021) similarly highlights the recurring theme of the search for a cure, and use of traditional healers. They also reflect that this is perhaps understandable, given the often very limited biomedical services available, and that different belief systems may be driven by poor access to health services and a lack of available treatment. This cure-searching inevitably comes with associated time and cost implications, further discussed below.

It is important to note that in many of the studies, participants were recruited at hospital settings, in-patient or out-patient clinics, or were attending a service such as a special school or one provided by an NGO project. This is likely to result in a selection bias, and one might expect that parents who attend such clinics may be more likely to have a better understanding of their child's condition and/or endorse biomedical causes. In practice, it seemed that *despite* attendance at a clinic, sometimes even for a long period of time, there was still limited caregiver knowledge. For example, in a study in Kenya, (Sandy et al., 2013b) all three case study families of children with intellectual disability had attended a clinic for more than 10 years, and a limited knowledge and understanding of learning disabilities remained as a theme.

It is also notable that in the majority of studies most participants were women, and mainly mothers, and these findings do not necessarily reflect understanding and beliefs of other

family members. Further research exploring these other perspectives would be valuable to enrich our understanding of the micro-system in which beliefs are shaped and decision-making is embedded, for example in relation to decisions to access health care.

Caregiver health

The negative impact of caregiving on both the physical and psychosocial health of the caregiver were two major themes, explored in approximately two-thirds of the studies.

Evidence across most studies which explore this aspect of the caregiver experience demonstrates high levels of caregiver stress and anxiety, and poor mental health. The literature indicates how a number of interwoven factors commonly negatively contribute to the psychological impact on the caregiver, which I further detail.

Stress can arise from caregiver's concerns about their child's development, and not knowing how best to care for the child, as illustrated in a study in Uganda which explored maternal experiences of caring for a young child with a neurological impairment (Nakamanya et al., 2015). Studies in Kenya and Tanzania found that it can also include concern about the child's future, including who will look after them following the death of a caregiver (Aldersey, 2012, Gona et al., 2011). High levels of stress and depression were also linked to the physical demands of caregiving, with exhaustion, lack of sleep, and lack of time for other household duties. These are further detailed in the section below on the Physical impact of caregiving.

Studies commonly detailed that the stress and worry can also be exacerbated by the shortage or absence of available services, and limited knowledge and understanding of the

condition, as already discussed. The often-substantial financial strain on families can be another key factor which contributes to poor mental health, as can levels of stigma, exclusion, lack of support and isolation, all of which will be further explored in subsequent sections of this review.

These findings, from countries in SSA, of poor caregiver mental health including high levels of stress and anxiety, aligned with other evidence globally on the health of caregivers of children (and adults) with a disability. A systematic review of literature on caring for a child with cerebral palsy in LMICs identified 46 articles, both qualitative and quantitative, and also found evidence of high levels of stress and depression (Pousada et al., 2013). Where studies included a comparison group, caregivers of children with a disability were consistently found to have higher levels of stress and depression and poorer QoL compared to caregivers who did not have a child with a disability. The review also highlighted the complex inter-related factors that contribute to poor mental health among caregivers, and this included the child's behaviour and cognitive problems, low carer self-efficacy, and low social suppor*t* (Pousada et al., 2013). This complexity of factors was also illustrated in a study conducted in Bangladesh which found that higher levels of caregiver stress were associated with poorer families, living in a rural area, and with a relatively older child (Mobarak et al., 2000).

Physical impact of caregiving

Another commonly described impact of caregiving is the physical impact, arising from a number of reasons. The physicality of caring can be quite substantial, with a child needing support throughout the day with all daily activities, such as bathing, walking or feeding. For example, in a study in Ghana, the considerable time invested in caregiving was illustrated by

a mother who took up to three hours to feed a child, which contributed to poorer levels of wellbeing (Den Besten et al., 2016). Carrying their child most of the time whilst often conducting other household tasks was another theme described in several studies. For example, an ethnographic study with two families in Malawi illustrated how one grandmother cared for her granddaughter with severe cerebral palsy, whilst also doing the household chores, often carrying her throughout the day (Barlindhaug et al., 2016). In a mixed methods study in Kenya (Geere et al., 2013) with 20 caregivers of children with moderate-severe motor impairments, many caregivers described overall feelings of poor health and extreme tiredness, combined with clinically-assessed chronic back pain.

The studies show that in these low-resource settings, a variety of issues exacerbate the physicality of caregiving in SSA. These issues include: the scarcity of assistive devices, the lack of access to child-care, lack of access to respite care whether from family members or more formal service provision, poor access to, and/or weakness of, public services available including health, education, housing, as well as other environmental barriers.

The scarcity of assistive devices is a common recurring theme across all countries which means that caregivers often have to carry a child, and/or taking a child to any service is more challenging (Geere et al., 2013, Singogo et al., 2015, Tigere and Makhubele, 2019). A study by Van der Mark illustrates how this can becomes increasingly challenging as the child becomes older and heavier (2019a).

The lack of access to child-care or respite, from family members or more formal childcare services, also exacerbates the challenges (Geere et al., 2013, Chiluba and Moyo, 2017). One study in South Africa illustrates the layering of issues which interact, with three in-depth case studies of children with learning disabilities. It describes the '*double trouble caring niche'*, that is, needing to combine full time care with household tasks and working, and a lack of available respite or support from other family members (Sandy et al., 2013ap.347). Whilst this study and others most commonly describe little or no provision of respite or childcare, another study in South Africa with 30 carers (Van der Mark et al., 2019a) described how such services were available, but some mothers chose not to use them because of mistrust in the service, with concerns about the poor quality of the service, neglect of the child, and possible abuse. This illustrates the complexity of both contextually-influenced supply and demand side issues around access to childcare and respite.

The physical environment can also further magnify the strain of caregiving. A study in Northern Kenya (Zuurmond et al., 2016) described a harsh and remote physical environment characterised by conflict, drought, and historical marginalisation. Caregivers had to travel long distances for very limited services, with few transport options. They might have to carry their child for more than an hour, to collect firewood and water. Toileting and the personal care of children, particularly when they were incontinent and/or unable to toilet themselves, was another strain of caregiving, exacerbated by the absence of latrines and limited access to water (Zuurmond et al., 2016).

The issue of incontinence and toileting and associated impact on dignity of the child, as well as the physical health of the carer, is touched upon only very briefly in couple of the studies. It is vividly illustrated by a photo-elicitation study conducted in Zambia (Hepperlen et al., 2021), which included a case study image of an older child sitting outside an inaccessible toilet, in extremely poor housing conditions. The child is unable to access the toilet themselves and is totally dependent on his mother to carry him onto a pot. Whilst this causes him embarrassment, particularly as he gets older, it also places an additional strain on the caregiver. The topic of incontinence is only recently gaining more attention and evidence in other studies in LMICs. Research and guidance for humanitarian settings (Rosato-Scott et al., 2019) highlights the negative emotional, social, practical, and monetary impact, on both the person with the disability but also on their caregiver. Managing incontinence requires significant extra water, soap, and time to bathe and wash clothes, pads, and bedding, which can be costly. Limited access to water, and stigma associated with incontinence, can further exacerbate these challenges.

Whilst the physical and emotional stress of caregiving has been evidenced globally, including in high-income settings (Brehaut et al., 2004), these publications from SSA clearly demonstrate how the wider socio-political and environmental context further accentuates the physicality and psychological strain of caregiving.

A critique of the studies in SSA, with a few exceptions, is in relation to exploring the gendered dimension of caregiving. Whilst it is common in the publications to state that most of the day-to-day caregiving of the child's needs falls upon a female member of the family,

normally the mother, the implications of this are often minimal or absent from the discussions. Yet gender norms are a key component of the macrosystem, and thus require greater attention in both understanding the caregiver experience as well as how caregivers engage with a parenting programme. This is a gap which will be explored in this thesis.

Access to services, with a focus on health services

Poor access to biomedical health services, and particularly rehabilitation services, is another common theme explored in a majority of the caregiver studies, alongside poor access to other specialist social and education services. I focus here particularly on issues related to accessing health and rehabilitation services. What is meant by 'access' to health care is a complex issue, with various conceptualisations of what this actually means (Levesque et al., 2013, Peters et al., 2008, Gulliford et al., 2002). For example, Peters et al (2008), describe four main dimensions which are key to access: geographic accessibility, availability, financial accessibility, and acceptability of the services, whilst Levesque uses the framework of a health care seeking 'journey' from need identification through to actually being offered services, and explicitly takes into account the person's capacity to access. It is generally agreed, whichever framework is used, that it involves a complex interaction of both supply-side and demand-side factors.

In terms of supply-side issues identified within this review, scarcity in human and physical resources was a very common issue in the caregiver literature. Whilst there is some evidence that it is more accentuated in the studies in rural contexts, it is also evident in urban settings (Geere et al., 2013, Zuurmond et al., 2016, Tigere and Makhubele, 2019, Namazzi et al., 2020, Patel et al., 2017, Dogbe et al., 2019, Kyerematenge et al., 2019, Gona

et al., 2011). This is summed up in a recent study in Uganda on caring for children with neurodevelopmental disability, where even in the capital city at one of the main hospitals the health system was described as '*incapable of adequately addressing the needs of such children due to lack of commodities, and human resource limitations*'. The study found a lack of equipment and understaffing in the physiotherapy department, and very limited outreach for caregivers that, even when available, was reportedly not found to be helpful by caregivers (Namazzi et al., 2020p.2).

This poverty of health service provision is also mirrored in other public services, and it is the combination of poor services that magnifies the burden of caregiving for children with disabilities. For example, a study in Zimbabwe details the historical socio-political context of service provision for persons with disabilities and with deteriorating services, combined with stigma, argues that this poses *'a significant burden on the female caregivers'* (Van der Mark and Verrest, 2014p.1420).

In addition, studies evidence poor health care workers' knowledge, attitudes, and skills in relation to working with children with developmental disabilities. Negative attitudes of staff, feeling mistreated, and a lack of any grasp of the emotional needs of carers, are highlighted in several studies in (Masulani-Mwale et al., 2016, Muthukrishna and Ebrahim, 2014, Singogo et al., 2015). Gona et al (2011) argue that these negative attitudes may be another contributing factor as to why carers then seek out traditional treatments, where they may feel treated with greater respect.

Little or no access to specialist rehabilitation services, and specifically to assistive devices, is a common theme. Where these are available, the equipment may be poor quality and/or the wrong size, which can further exacerbate the physicality of caring. The cost of the equipment, time to travel for equipment, and travel expenses, all further add to the challenges (Patel et al., 2017, Dogbe et al., 2019, Kyerematenge et al., 2019, Paget et al., 2015, Nakamanya et al., 2015, Van der Mark et al., 2019a). These findings align with studies which have specifically focused on the challenges of provision, more broadly, of rehabilitation and specialist services (Hashemi et al., 2020, Bright et al., 2017). For example, a survey of rehabilitation support for children in rural Kenya highlighted a range of weaknesses in the system, including inadequate resources, limited staffing, poor transport options to the urban location of many services, and care driven by professional training rather than child needs (Bunning et al., 2014b).

In terms of demand-side issues affecting access to health services, there were several complex and interconnected issues. Whilst some caregivers stated that they saw some benefits to the rehabilitation process, even when it was expensive (Barlindhaug et al., 2016), it was more common for a range of barriers to be emphasised. These included direct cost of medications, and/or not having access to a health insurance to cover costs (Dogbe et al., 2019, Lamptey, 2019). More commonly, indirect costs such as transport costs were noted (Hartley et al., 2005, Pretorius and Steadman, 2018). These are likely to be more of a challenge where families have to travel longer distances, especially from rural areas, for any specialist services, which are often located in urban settings (Gladstone et al., 2017, Patel et al., 2017, Kyerematenge et al., 2019). This latter issue of poor transport systems, combined

with long distances to services, also mirrors one of several findings of a survey into rehabilitation support available for children with disabilities in rural Kenya (Bunning et al., 2014b).

The fear of stigma has also been shown in this review to be yet another factor influencing decisions to avoid public transport, which can add another layer of difficulty in accessing services (Patel et al., 2017). The lack of specialised services (health, education and social) for children with intellectual disability, and challenges in accessing what services do exist, was similarly highlighted in the review by Mkabile (2021).

These experiences around substantial interacting, demand- and supply-side barriers to health services for children with disabilities, and the strain this puts on caregivers, resonate with similar experiences in several other studies from other LMIC settings (Yousafzai et al., 2011, Alaee et al., 2015, Huang et al., 2012, Matt, 2014, Paget et al., 2015, George et al., 2014).

As already detailed, the majority of participants in studies identified in the review were recruited from those already attending tertiary hospitals, both inpatient services and clinics. There were also twice as many studies conducted in urban settings. This may have introduced a bias to the findings, and not adequately captured the particular experiences of families in the rural settings, with typically even fewer available services. The implications for the gendered nature of caregiving, and the complexity of decision-making around access to services made at a household level, is worth greater attention. This would also tie in with the recommendations of a recent review by Hashemi et al (2020), that examined barriers to

health care issues for persons with disabilities. It described the complex, dynamic, and cumulative nature of cultural beliefs, attitudes, informational and practical barriers on both the demand and supply side. The paper argues that these dynamics need to be better understood, including how decisions are made at a household level, in order for a more nuanced approach to improving access to services.

Social support networks and isolation

The issues of isolation and lack of social support are two other major intertwined threads running through research on caregiving and is woven into narratives across all countries and in both urban and rural settings. This combines with the lack of professional support already explored in the previous section.

Caregivers can feel like they are the 'only one' with a child with this condition (Machuki et al., 2016). They can feel isolated within their families and in the community when they are not invited to events, no longer engage in the workplace, and/or choose to stay at home. The reasons for this isolation and narrowing of support networks were various and often mutually reinforcing. Common themes were family systems breaking down and stigma, experienced or perceived. The issue of family breakdown is illustrated in two papers from the same study in Ghana (Kyerematen et al., 2019, Dogbe et al., 2019) that examined different facets of the caregiver experience. Thirty of 40 caregivers interviewed described conflict in the marriage after their child's diagnosis, not only from spouses but also from the in-laws. The women also reported that they normally bore the brunt of the blame for having a child with a disability and felt neglected.

Some caregivers 'elect' to self-exclude themselves and their child, for a layering of reasons. For example, in one study in South Africa (Pretorius and Steadman, 2018), the caregivers described not having the energy to socialise, even if they wanted to, and this was compounded by the mother feeling that it was their responsibility to look after the child. Other factors for isolating at home included having concerns about the safety of their child, particularly within a violent environment, such as in the context of a South African Township (Van der Mark et al., 2019a), and concerns about the child's behaviour in public that might then be stigmatised (Mofokeng and van der Wath, 2017, Muthukrishna and Ebrahim, 2014, Singogo et al., 2015). The consequence of this isolation, as described in one study in Ghana which used participatory tools to explore factors which contributed to caregiver wellbeing, were that mothers were sometimes made to feel like a '*prisoner in their own house' (Den Besten et al., 2016p.98).* Lack of support from the family may also contribute to worrying about who would look after their child in the future (Mkabile and Swartz, 2020, Nakamanya et al., 2015).

The complexity, interlinks, and reinforcing nature of different factors, was clearly illustrated in an ethnographic study with 30 mothers of children with disabilities in an impoverished township in South Africa. This paper (Van der Mark et al., 2019a) describes the resultant '*small worlds'* of the mother. Only five of 30 mothers said they received some family help on a daily basis and two main reasons were highlighted: the mother's lack of trust in others, and other family members not willing to give their support. The isolation was then magnified by the poverty of the setting, lack of services, concerns about the safety of the child in the violent setting, and community stigma. A second paper from the same study

explored in greater depth the mothers' adaptive behaviour and sought to understand why mothers appear to '*retreat*' from external support; a key reason given was that it is a behaviour which enables them to avoid the negative responses within the family and community (Van der Mark et al., 2019b). This highlights how caregiver isolation and lack of support intersects with the caregiver experience of stigma, and this is explored further in the next section.

This narrowing of support networks following the birth of a child with a disability is aligned with findings from studies in other LMICs, even with very different cultural norms. For example, a qualitative study with parents of children with cerebral palsy in Iran highlighted the unsupportive family, and seclusion of the child and parent. Parents felt there was little understanding by relatives and community members and provision of almost full-time care also limited their social interactions (Alaee et al., 2015). Studies, both mixed methods and qualitative, in India, Taiwan, and Bangladesh similarly describe parents reporting that they receive little or no support from families and the community, being marginalised, and feeling isolated (Gupta et al., 2012, Huang et al., 2012, Zuurmond et al., 2015).

Experiences of stigma

Stigma is a complex social construct, and there have been various theories, categories, and concepts, which are explored in greater detail in **Chapter nine**. Goffman pioneered work on stigma in the 1960s, and defined stigma as as an '*attribute that is deeply discrediting'* and reduces the bearer from *'from a whole and usual person to a tainted, discounted one'* (Goffman, 1963p.3). His theory was further developed and reframed over the next fifty

years to explain health-related stigma. For the purpose of this review , the categorisation adopted is internalised, social, and structural stigma (Corrigan et al., 2005, Livingston and Boyd, 2010). Internalised stigma refers to the individual, and to felt or perceived stigma at the micro level. Felt stigma is the individual's internal feelings, such as a sense of shame, or anticipation about stigma, such as a fear of encountering possible discrimination (Scambler, 2009). Social stigma is enacted stigma or public stigma, operating at the micro and meso level and is interpersonal in nature. Felt stigma describes overt examples of discrimination experiences (Scambler, 2009), whilst structural stigma or institutional stigma operates at the macro or systems level (Link and Phelan, 2001, Link and Phelan, 2014, Weiss et al., 2006).

Whilst there are examples given of positive attitudes towards a child's disability, an overall theme across approximately two-thirds of the empirical studies reviewed was of high levels of stigma woven into the narrative of caregiving. Stigma clearly plays an influencing role in many of the themes of caregiving experience previously discussed, but few studies then explore this in detail. There were only three empirical studies from the SSA context which explored the different strands of stigma experienced by caregivers in any depth; two in Ethiopia and one in DRC (Tekola et al., 2020, Tilahun et al., 2016, Aldersey et al., 2018). The narrative synthesis of experiences of caregiving children with intellectual disability (Mkabile et al., 2021) reported that most of the nine studies refer to high levels of stigma experienced.

In terms of internalised stigma, a common issue identified across many studies was of caregivers' and/or family members' feelings of shame attached to having a child with a developmental disability. A mixed methods study in Ethiopia surveyed 102 parents of children with developmental disabilities attending a clinic; 45% of caregivers of children reported feeling ashamed about their child's condition and 43% said they were worried about being treated differently (Tilahun et al., 2016). The same study found that the level of stigma reported did not depend on the type of developmental disorder, gender, or age of child, nor on caregiver age or level of education. A mixed methods study in Kenya similarly reported high levels of stigma experienced in a large study (N=285) of caregivers; 61% had experienced stigma from others, 64% reported self-stigmatisation. Stigma is complex to assess and it was beyond the scope of this review to critique the reliability and validity of the questions used to assess stigma. However, the findings were also complemented by qualitative data which indicated the mothers feeling blame, directed particularly at them.

Social stigma is a very strong theme in the literature. This is not only directed at the child with the disability but also experienced by their caregivers experiencing negative looks, negative language, being shouted at or insulted by both community members and other family members (Aldersey et al., 2018, Van der Mark and Verrest, 2014). In the extreme, caregivers in two studies talked of feeling pressurised from family members or a neighbour to kill the child, linking back to traditional beliefs, in studies in Malawi and Ghana (Kyerematen et al., 2019, Masulani-Mwale et al., 2016). Social stigma manifests in exclusion from family events, but also in the day-to-day lived experience with the family. It is the latter which sometimes seemed particularly painful, as exemplified in a study in

Northern Kenya, where a mother of a three-year-old child with cerebral palsy described in tears what support she received from her sister: '*My sister does not want to help me carry my child. She provides for us and helps me a lot with money and food. But she doesn't want to associate with my child because he is disabled. She does not carry him at all'* (Zuurmond et al., 2016p.5).

In terms of understanding the drivers of stigma, the recurring reason given is the link back to the traditional beliefs of sorcery and witchcraft. Furthermore, these views can be reinforced by traditional healers who may, in some cases, attribute the disability to evil spirits or misdeeds (McConkey et al., 2016). Fear linked to the behaviour of a child was identified as another driving factor in an Ethiopian study (Tekola et al., 2020). This latter publication is one of the few studies in the review that explored the socio-cultural underpinnings that shape stigma, with the concept of '*Yilunta*' as central to Ethiopia culture. This relates to the importance of honour and family pride. Essentially, by excluding mothers and a child with a disability, the family avoids bringing shame upon the family. This same pride may also be a reason for a caregiver not asking for help.

What is common across these studies was that blame is commonly more attributable to the mother, often driven by the husband and/or husband's family. In some examples this might result in divorce or abandonment of the mother (Kyeremateng et al., 2019, Tigere and Makhubele, 2019, Aldersey, 2012). This is illustrated in a study in Zambia of mothers with children with cerebral palsy: '*I struggle and the fact that my husband and his family accused me of being the cause of the condition it is difficult*' (Singogo et al., 2015p.4). It is therefore

perhaps surprising that the gendered dimension of this experience is not further unpacked. Of course, most of the research was conducted with primary caregivers, who were mothers, and it would be useful to understand more about the perspectives of fathers and other family members.

These findings do reflect the wider body of evidence globally which shows that people with disabilities experience various forms of stigma and discrimination (World Health Organization and World Bank, 2011b). At the same time, reflecting the complexity of this social construct, the literature also indicates the value of contact with persons with disabilities as pivotal for reducing stigma (Allport et al., 1954, Smythe et al., 2020a, Gona et al., 2018). Several publications from China and Taiwan explore in greater detail internalised and social stigma experienced by the caregivers of children and adults with intellectual disabilities and cerebral palsy (Yang, 2015, Mak and Cheung, 2008, Huang et al., 2012, Heng-hao, 2009, Chiu et al., 2013). However, whilst this review indicates the influencing role that stigma can play in many of the themes of caregiving, there are very few studies which explore this in any depth, and the implication for caregiving in the SSA context. One research objective of this thesis is to explore the issue of caregiver stigma in the Ghana context, and the implications of this for caregiving and engagement with a training programme. This is further detailed in **Chapter nine.**

Poverty and the economic costs of caregiving

Finally, whilst it has been a cross-cutting issue throughout this literature review, the issue of poverty and associated economic costs of caregiving are a key recurring theme which

impacts on and interacts with many aspects of the caregiving experience. This theme emerges in approximately two-thirds of the studies. The economic costs can be a combination of direct and indirect costs associated with caregiving. The direct costs include the costs of seeking treatment, as well as associated costs such as transport. Indirect costs include the difficulty in combining work with care.

In terms of indirect costs, the inability to return to jobs or having limited time for income-generating activities following the birth of a child with a disability is a main area of impact (Kyerematenge et al., 2019, Oti-Boadi, 2017, Mkabile et al., 2021, Sandy et al., 2013b). The lack of financial support from spouses or family members further compounds this experience (Nyante and Carpenter, 2019).

A fairly commonly expressed view raised in the literature from SSA is the inability to cover even basic needs for their child and family (Gona et al., 2011, Gladstone et al., 2017, Hartley et al., 2005, Van der Mark et al., 2019a). In general, the economic costs of caregiving were not explored in any detail in these publications.

These economic consequences of caregiving have, in turn, been shown to have a psychological impact on caregivers. Parents may well have been living in poverty already , and as a result of having a child with a disability they now spiral into deeper poverty (Den Besten et al., 2016). A study in Uganda (Namazzi et al., 2020) with 14 caregivers with children with severe neurodevelopmental disabilities highlighted that the combination of high care costs, inability to return to income-generating activities, nursing challenges, and

stigmatization, were described as '*impoverishing and imprisonin*g' to caregivers. The inability to cover the basic needs for their families can also have a psychological impact, described as contributing to '*profound distress'* and a *'sense of failure'* (Van der Mark et al., 2019a).

In terms of the wider body of literature on disability, it is beyond the scope of this review to explore the extensive literature on poverty and disability. However, there is a well-established body of evidence that demonstrates that poverty and disability are interlinked for persons with disabilities and their families. Disability can increase the risk of poverty through lack of access to employment and educational opportunities, and increased household expenditure on care and support. In turn, poverty can increase the risk of disability through poor and untimely access to services, food insecurity and malnutrition, poor work conditions and a risky environment (Banks and Polack, 2014, Groce et al., 2011, Mitra et al., 2011, Banks et al., 2017b). A recent publication from South Africa (Hanass-Hancock et al., 2017) explored in detail the out-of-pocket expenses of those with disabilities and their caregivers, and highlighted the complexity of issues. The care and support needs varied by disability type and whether there was a need for specialist support, such as assistive devices. The costs were mainly indirect costs, that is, the time cost of the caregiver who is looking after them, and therefore not working. In terms of accessing services, costs depended on the frequency of needing to attend health care facilities and were generally found to increase with the level of severity of disability. Finally, the costs of participation in the home or community related to issues such as transport and assistive devices, and varied depending on the environment. A strong argument has been made for not only more data to demonstrate the link between poverty and disability (Banks et al., 2017b), but for a more

nuanced understanding of what poverty means in practice for the individual and the wider household (Groce et al., 2011).

Through this thesis I aim to better understand what poverty means in practice for caregivers who are engaged with a training programme. There also seems to be a gap in understanding the relationship between living in poverty, caregiving, and gender. This is also explored in this thesis, in terms of understanding the pathways of change in the parenting programme, and the relationship with caregiver agency, and caregiver experiences of stigma detailed in **Chapters eight** and **nine**.

Coping responses and the positives of caregiving

Finally, it is important to emphasise that, whilst much of the research in SSA emphasises the 'burden' of caregiving and the various challenges faced by families, it was also apparent that many children with disabilities were loved and cared for, despite extremely difficult circumstances.

The most commonly reported coping strategy was spiritual and religious support, and this was illustrated in studies from across all country settings, and both urban and rural contexts. The caregivers frequently used prayer, and rationalised that their child's disability was part of God's plan. This is typically illustrated in a study with caregivers in DRC where one mother explained that she will '*put everything in God's hands, because the child also knows God, and our Lord will take care of* us' (Aldersey et al., 2018p.129). There was a smaller number of examples where the role of religion was not always positive, for example, negative

attitudes towards disability experienced from attending in prayer camps in Ghana (Lamptey, 2019). It is interesting to note that whilst spiritual beliefs were a coping mechanism, there was a notable absence of reported material or social support provided by a church or other faith-based institutions.

Having support from others within the family and community was another identified protective factor that helped carers to cope. The importance of '*having hope'* was another dimension illustrated in a study in Zambia (Hepperlen et al., 2021) which was facilitated through talking to parents who have a child with a similar condition. Renewed hope was also identified as a contributing factor towards caregiver agency in a study of self-help groups in Kenya (Bunning et al., 2020) which is further explored below in the section on Interventions.

Families and caregivers were in some instances shown to adapt and develop new skills, as a positive aspect of the caring role. For example, a study by Gona et al (2011) showed how parents developed problem-solving skills in improvising to provide therapy at home. Other studies described improvements in self-esteem, notably, levels of pride, self-respect, and self-efficacy which some mothers felt in knowing they were taking good care of their child (Van der Mark et al., 2019b, Muthukrishna and Ebrahim, 2014).

The positives of caregiving in acquiring new skills, and the contribution towards caregiver empowerment has been illustrated in a small number of studies from LMICs. For example, in

Pakistan society, where women traditionally are restricted in what they can do outside of the home, caring for a child with disabilities often meant that they sought a range of services, which enabled women to move their typical traditional roles (Yousafzai et al., 2011). Studies in Taiwan and South Africa also showed how collective mothers' groups learned about disability rights and became effective advocates for their children, (Heng-hao, 2009, De Sas Kropiwnicki et al., 2014). It has also been demonstrated that parents can be effective trainers on disability if they are given suitable training and support, which is often not made available to them (McConkey et al., 2016).

Results - evidence on the impact of parenting programmes

A total of 14 papers from SSA were identified on parenting programmes for caregivers of children with disabilities, not including the four papers from this PhD. These four papers covered 11 programmes (two papers detailed one programme in Kenya, and two papers covered a second programme in Kenya). The studies were conducted in: Kenya (2), Malawi (3), South Africa (3), Tanzania (1), Zimbabwe (2). Four programmes were delivered in urban settings, two in peri-urban settings, three in both urban and rural sites, two in rural sites. A summary overview of the papers is provided in Table 3 Summary of parenting intervention studies.

Table 3 Summary of parenting intervention studies

Author/Date	Title	Study Design/summary methods P=process, I=Impact, F=Feasibility, A= Acceptability	Country/ Urban/ Rural	Intervention (summary)	Main outcome measures	Summary of Key Results
(Mlinda et al., 2018)	The effect of a practical nutrition education programme on feeding skills of caregivers of children with cerebral palsy at Muhimbili National	I: RCT: 2-block stratified sample from children attending hospital. children with CP <5 years. Intervention arm (n = 63) and control groups (n= 47).	Tanzania: Urban	Clinic based. Intervention arm: 6-8 **group** education sessions on nutrition education & positioning for feeding + one home visit. Control group: general care at clinic that included physio services, general health, nutrition guidance.	*Feeding skills, *caregiver stress.	Mixed results: Significantly improved caregiver feeding skills on range of measures. Caregiver's reported being less stressed (AOR = 2.53, 95% CI: 1.04–6.13), child's mood was improved (AOR = 3.15, 95% CI: 1.33–7.474). No significant change in oral motor feeding skills (AOR = 1.67; 95% CI: 0.72–3.91) and functional feeding skills (AOR = 2.28; 95% CI: 0.86–6.06).
(Dambi and Jelsma, 2014b)	The impact of hospital-based and community based models of cerebral palsy rehabilitation: a quasi-experimental study	I: Quasi-experimental: Convenience sample from attendees at clinic. Survey n=46 caregivers (F= 43, siblings=4). Children received community rehab with parents (n=20), or outpatient service at hospital (n=26).	Zimbabwe: Peri-Urban	Community & clinic setting. In both arms, therapeutic treatment. Community arm: 2 x per month **group** activities; educational sessions, stress management, experience sharing, option to participate in support group activities such as income generation activities.	*Caregiver Strain Index (CSI), *modified Medrisk satisfaction with physio services. *compliance	Mixed results: In outreach-arm, 6% more improvement in child motor function. No difference with caregiver strain, greater satisfaction with services (p < .001), greater compliance as compared to hospital arm.
(Dambi et al., 2016)	Does an educational workshop have an impact on caregivers' levels of knowledge about cerebral palsy? A comparative, descriptive cross-sectional survey of Zimbabwean caregivers.	I: Post-test design: Cross sectional survey, n=49. Comparison group did not receive workshop.	Zimbabwe: Urban	3-day workshop: presentation, aetiology, management of cerebral palsy.	*Caregiver knowledge	Significant improvement in knowledge for those who attended workshop 17.4 (SD 1.5), compared to those who did not attend workshop 13.8 (SD 2.5),(P < 0.001).

(van Aswegen et al., 2019)	The effect of the Hambisela programme on stress levels and quality of life of primary caregivers of children with cerebral palsy: A pilot study	I: Pre/post-test pilot. N=18 caregivers of children with CP. Convenience sample from therapy centre.	South Africa: Urban	Hambisela, a **group-based educational** intervention, once a week/ over 8 consecutive weeks at baby clinic.	*Stress (Parenting Stress Index-Short Form -PSI-SF), * QOL (PedsQLTM-FIM)of primary caregivers	No Impact: 14 (87.5%) with clinically significant stress pre-test & 11 (68.8%) at post-test (p=0.72).No significant change in QOL (p = 0.85).
(Bunning et al., 2020)	Empowering self-help groups for caregivers of children with disabilities in Kilifi, Kenya: Impacts and their underlying mechanisms	I/P, Mixed methods, pre/post-test: questionnaires included (Community Disability profile & Multi-dimensional scale of perceived support)(n = 75), SSIs (n = 36). Groups recruited through various community groups. Purposive convenience sample of participants.	Kenya: urban/rural	Facilitated intervention to **groups** (N = 154) over 6 months. Topics included: economic empowerment, personal situation, peer support, community inclusion, access to health & education.	Caregiver identified change, mechanism of change	Overall positive change: Significant change in improvement in social support, perceived reduced severity of child's disability. Positive examples of community recognition/inclusion, acceptance & wellbeing, group coordination and capacity built. Newly developed skills from business &, social connectedness linked to empowerment.
(Storbeck and Pittman, 2008)	Early intervention in South Africa: moving beyond hearing screening	I/P: Mixed methods: pre/post-test design. child assessment (n=10), satisfaction survey n= 11 families	South Africa: Urban/ rural	**Home-based** over 12 months. Weekly visits with parent advisor. Option to receive services from a deaf mentor. Delivered to 33 infants & families	Child language development, parent satisfaction	Positive outcomes for child language development assessment. 10/11 parents rated service excellent. Emotional support/communication with child was ranked as greatest benefit. High value & acceptability for parent advisor. 100 % recommend the program.
(Kelly et al., 2012b)	A Pilot Study of Early Intervention for Families with Children at Risk of an Intellectual	I/P Post-test SSIs conducted 9 months after pilot. Convenience sample 10 families, 3 Staff as portage trainers, 4 CHVs.	Malawi: Rural	Community health visitors (CHVs) support parents in **home** with portage. Trained & supervised by portage trainers.	CHV and parent perspectives on process & impact	CHVs engaged & happy with role, identified more training needs. Good parent satisfaction level, varied areas of child progress, increase in male engagement. Challenges

	Disability in Northern Malawi					identified included lack of community support.
(Bunning et al., 2014a)	Caregiver Perceptions of Children who have Complex Communication Needs Following a Home-based Intervention Using Augmentative and Alternative Communication in Rural Kenya: An Intervention Note	I+P: Mixed methods. N=9 A pre-post-test design. Recruitment of caregiver from Education Resource Centre register	Kenya: Rural	**Home-based** programme. Use of low-tech locally resourced materials. Augmentative and alternative communication offered at home over 6 months with one monitoring visit every month.	*Parent perceived impact measures, including participation opportunities * The Communication Profile adapted	Positive outcome: Parents viewed children differently in terms of bodily structures and functions
(Gona et al., 2014)	A home-based intervention using augmentative and alternative communication (AAC) techniques in rural Kenya: what are the caregivers experiences?	I+P: Mixed methods. N=10. A pre-post-test. SSIs:	Kenya: Rural	As above	*Child's communication with caregiver and others *caregiver's communication skills, *available support, *caregiver's future outlook	New ways of communication tested, realistic expectations, positive shift in caregiver attitude, increased sense of community support.
Feasibility & acceptability studies						
(Lynch et al., 2018)	'I have learnt to love the child and give opportunities to play with peers': A feasibility study of the training programme to support parents	P/F: Mixed methods: 20 SSIs, post-intervention, 1 FGD (N=6), 10 observations with carers in home. Children identified through key informant method.	Malawi: Rural/ urban	3-day **group** training to 30 children with VI: childhood development and VI, group activities, role play, development materials..	Acceptability, feasibility.	Acceptability of approach. Feasibility: some challenges in rural areas to support outreach, given human resource capacity issues. Improved attitudes towards children with disabilities, improving relationships and responsiveness in their interactions.

	of young children with visual impairment in Malawi.					
(Masulani-Mwale et al., 2019)	Development of a psycho-social intervention for reducing psychological distress among parents of children with intellectual disabilities in Malawi.	P, F&A: Intervention development process. Final stage: 2 FGDS with caregivers, N=14 (F=8, M=6). Recruitment from CBR clinics.	Malawi: Urban	Parent **group** training to develop parent coping skills. A broad range of topics covered on child disability, and improving caregiver skills, and broader issues around rights. (Full details of final content and modality of delivery not detailed).	Acceptability, Feasibility	Parents enjoyed training, improved knowledge about child's condition, retained information, identified areas for improvement: extra training, transport, content & memory retention.
(Ngubane and Chetty, 2017)	Caregiver satisfaction with a multidisciplinary community-based rehabilitation programme for children with cerebral palsy in South Africa.	P. Survey, FGDs. Recruitment from 3 healthcare sites.	South Africa: semi-rural	**Group** & individual format: Weekly sessions, 6-week rehab programme from team therapists. Mix of presentations, demonstrations, **group** therapy.	*Satisfaction levels, *caregiver experience	Overall reported high levels of satisfaction.

In terms of the target groups for the interventions: five interventions targeted caregivers of a child diagnosed with cerebral palsy, two with children with varied developmental disabilities, two with children with sensory disability, and two with children with intellectual disability (ID). The studies were very mixed in terms of their intervention design, but all aimed to equip caregivers to provide and improve home-based care to their child. Some programmes were delivered in a home/community setting, whilst others were delivered in a clinical setting, sometimes combined with a home visit. The majority were delivered through working with a caregiver group meeting, sometimes combined with a targeted individual component, such as a home visit. Only three interventions targeted a service to families in their home (Kelly et al., 2012b, Storbeck and Pittman, 2008, Bunning et al., 2014a). Six studies assessed programme impact, or a combination of impact and process, and I summarise these first.

Overall, the impact results were mixed across the six studies. One study, using a randomised controlled trial (RCT) design, (Mlinda et al., 2018), examined the impact of a nutritional group education programme on caregiver feeding skills for children with cerebral palsy attending a paediatric clinic in Tanzania. This was compared to standard routine care with physiotherapy at the clinic. It showed mixed results, with caregivers in the intervention arm reporting feeling less stressed and improvements in the child's mood. There were improvements in feeding skills, but these were not significant.

Two studies with caregivers of children with cerebral palsy were conducted in Zimbabwe by Dambi and colleagues (2014a, 2016). A quasi-experimental study compared hospital

standard therapy with a community-based intervention. Both groups received some therapeutic treatment, and in addition, the community group received twice- monthly sessions that offered a mix of support group and individual sessions. There were mixed results with some improvement in the community arm, including greater satisfaction with the services, with better adherence to attending sessions, but no significant changes in caregiver wellbeing in terms of levels of caregiver strain. However, the study had a number of limitations; a small sample size and a relatively high loss to follow up may have resulted in inadequate power to detect change. Overall, the community arm had older children with more severe levels of cerebral palsy, although the fact that adherence was still high, is positive. The second (Dambi et al., 2016) evaluated the impact of a three-day educational workshop for caregivers on the management of cerebral palsy. Whilst it demonstrated high levels of knowledge, baseline knowledge levels were not known, given the post-test design. Whilst improvement in knowledge and understanding is important, it is limiting to only assess knowledge change. The study also used a convenience sample, selecting those who had elected to join the training, which may also introduce a bias.

A pre-post-test design pilot study in South Africa (van Aswegen et al., 2019) assessed the impact of a group-based educational programme (Hambisela), covering different aspects of care and support. Overall there was significant impact on caregiver QoL and stress. However the sample size (N=18) was small, and it may not have been powered enough to detect change. Finally, the only larger-scale impact study with caregivers self-help groups in SSA was conducted in Kenya by Bunning and colleagues (2020). This examined both impact and underlying mechanisms of caregiver for self-help groups; groups were established over a

ten-month period, followed by a facilitated intervention on a range of topics covered for the remaining six months. It assessed a wider range of outcome measures, and showed positive results, including parent-reported measures of social support, perceived reduction in the severity of the child's condition, and examples of inclusion and community attitudinal change. Increased agency was facilitated by processes which included: group cohesion, acquisition of business skills, community recognition and renewed hope for their child. A second paper on the same study examined the underlying mechanisms of these self-help groups (Gona et al., 2020) and success factors included the value of strong group leadership, and a successful income generating activity (IGA).

The second category of interventions were programmes that targeted individual families in the home-setting. In total, three programmes were evaluated, two targeting improved language development, and a third offering a portage programme. Again, they were heterogenous in their design of intervention, and target group, and so it is hard to draw any conclusions. 'HI HOPES' for children with hearing impairments by Storbeck et al (2008) included weekly visits from a parent advisor over a 12-month period. The results showed positive improvements for child language development, although the number of children assessed at endline was small (n=10), and children were excluded from the language assessment if there were severe additional disabilities. Parent-reported satisfaction was high, but again the numbers were small, with the overall response rate for parent survey of those who participated low (55%). Whilst the programme stated it was a holistic approach, the outcomes reported on were limited, and it would have been valuable to have a broader set of measures, including an understanding of the mechanisms, such as the role of a parent

advisor and/or deaf mentor. Two papers reported on a programme that promoted augmentative and alternative communication methods in the home for children with developmental disabilities (Gona et al., 2014, Bunning et al., 2014a). Whilst it was a small study (N=9) it demonstrated a number of positive child outcomes, not only on language development but also on wider child community participation, and processes indicated positive shift in caregiver attitudes and uptake of new communication methods, with more realistic expectations. Finally, a third small (N=10) pilot study (Kelly et al., 2012b) evaluated a home-based portage programme delivered through community health volunteers(CHVs) and indicated parent satisfaction and some areas of child progress. However, it was a post-test design, so whilst promising, care needs to be taken in interpreting the results on impact.

The remaining papers identified in the review were all focused on examining the feasibility and acceptability of intervention and were small pilot studies (Lynch et al., 2018, Kelly et al., 2012a, Masulani-Mwale et al., 2019, Ngubane and Chetty, 2017). Overall, sample sizes were small, which can be common with pilot studies (ranging from 9- 26 caregivers), and outcome measures were largely parent-reported measures of satisfaction with the intervention. Whilst they all showed high levels of feasibility and acceptability, which is promising, they would have benefited from testing out a broader range of outcome measures in line with the ICF, including measure of participation and activities, and caregiver and family-level outcome measures, such as QoL measures.

In summary, there is very limited evidence from SSA on the impact of caregiving programmes for children with developmental disabilities. Findings were mixed, with some studies showing improvements in caregiver knowledge, skills and satisfaction and others demonstrated no significant change in measures of QoL. There were several weaknesses in the quality of these studies which included small sample sizes, and the use of assessment tools which were not necessarily validated in the local context. Commonly, convenience samples were used of families who were already using a service or attending a health facility, and therefore it is not likely to be representative of the general caregiver population and may introduce a bias as these parents are arguably more motivated to seek services and/or elected to attend the trainings. The impact studies, overall, were also of a weak design, for example, with no comparison groups or post-test design only. That said, when working with families with children with disability there are also ethical reasons for not employing experimental designs such as RCTs, or studies that are quasi-experimental, and this is briefly explored in **Chapter four** on Methodology (see section on Overall Study Design). The studies also varied widely in both their intervention and study designs, with widely varying outcome measures, which makes it difficult to compare results, and draw any conclusions around impact or process.

Overall, with a couple of exceptions, there was often a narrow set of outcomes assessed across the studies. It would be valuable to include a wider range of measures that explore impact on both the caregiver and the child. The use of caregiver groups was popular as an approach, but with the exception of the paper by Bunning (2020) there was little exploration of the mechanisms of how these groups operate to effect caregiver agency and change. There is an evidence gap here in terms of understanding if, and how, this translates

in change in care and support, and in turn, impacts on child-level outcomes. Given the interventions largely focused on female caregivers, there was surprisingly little consideration given to any gender issues, and of the wider context in which care and support is embedded.

A systematic review of paediatric cerebral palsy in Africa (Donald et al., 2014) similarly concluded that there is a lack of information on the efficacy of home-based interventions from Africa. Further, the evidence for the effectiveness of parenting programmes appears similarly limited across other LMICs. Yousafzai and colleagues (2014) conducted a review of home-based care programmes in LMICs and only six studies were identified. The two SSA studies have already been reviewed above (Gona et al., 2014, Kelly et al., 2012b). The other four studies included two papers from Bangladesh; one found a positive impact on feeding practices (Adams et al., 2011), and another evaluated an outreach model of a parent training programme and found some improvements in maternal knowledge and adaption, but mixed results in terms of parental stress (McConachie et al., 2000). A community programme conducted in India (Sen and Goldbart, 2005) demonstrated valuable lessons on setting up community support for children with disabilities, and a study of the efficacy of a home-based programme for children with intellectual disability in Vietnam (Shin et al., 2009) demonstrated some significant impact on child functioning and activities. However, the review summarised that whilst these few studies demonstrated some positive impacts on both the caregiver and child, they also shared several weaknesses in study design, including small sample sizes, limited information on the validity and reliability of some of the assessment tools, high attrition rates, and mixed quality of outcome measures.

Limitations

There are a number of limitations to this literature review. Grey literature was not included, which may have resulted in some missing information especially in relation to the literature on interventions. This review only included papers in English, and thus is likely to have resulted in exclusion of some studies from Francophone Africa. Search terms for individual conditions, such as autism and epilepsy, were not included, and this would have further enriched this review. For a scoping review it would be necessary to have a second reviewer to check all stages of the inclusion/exclusion stages of selecting papers. It would also have benefited from a formal quality assessment of the studies. Finally, in the review of interventions, studies about 'support group/self-help' groups where there was no 'formal input' offered were excluded. However, there may be valuable information from understanding general support group processes, particularly in relation to exploring and understanding the sustainability models of parenting programmes.

Conclusion

This literature illustrates the multi-faceted and interacting factors issues that directly and indirectly affect the lives of caregivers and their child in the SSA context. In the SSA context, whilst there are differences across studies, this review shows that many of the experiences are shared across different countries and contexts. Whilst evidence highlights how many caregivers do their best to care for their child, and develop and harness various coping strategies, the resounding picture was of the heavy strain of caregiving, exacerbated by the socio-political and environmental context.

Low levels of knowledge and understanding about the child's condition, exacerbated by the scarcity and weakness of existing services, are common themes in different settings. Many studies demonstrate the psychological impact of caregiving, with high levels of stress and anxiety, as well as the physical toll on the caregiver. Isolation and lack of support emerge from the literature, which in turn interact with disability-related stigma. However, there is more limited in-depth research examining how the caregiver experiences stigma, and the repercussions for care and support processes. Poverty was also identified as a key cross cutting issue, with households further depleted by the additional costs of care, as well as the time needed for caregiving, with loss of time for income-generating activities. These multi-faceted challenges are influenced by, and in turn influence, factors at different levels of the child-caregiver ecosystem. The aim of this thesis is to explore these interacting factors in greater depth, in the context of caregiver engagement in a support programme.

One of the limitations identified in this review was the lack of attention to the gendered nature of caregiving, and any implications for a model of care and support. This needs to be better understood in the development and delivery of any parenting programme. Whilst most studies were conducted with female caregivers, many of these studies then went on to discuss 'families' and 'parent' experiences and did not explore the fact that caregiving is gendered, with all the implications of this at the household and community level. More broadly, across both the research on caregiver experience and interventions, there was a paucity of discussion around gender, beyond stating that that the burden of caregiving is largely on women, or that blame was commonly attributable to the mother. There were some notable exceptions to this (Muthukrishna and Ebrahim, 2014, Van der Mark et al.,

2019b). This is an important issue which is explored further in this thesis across the different chapters, for example, in terms of understanding the mechanism of caregiver empowerment **(chapter 8),** or how caregivers experience stigma **(chapter 9).**

The second component of this review highlighted the dearth of intervention studies for parents/caregivers with children with disabilities in SSA, despite the fact that global strategies and guidance already discussed in **Chapter one,** emphasise the central importance of the family for a transformative change towards children thriving. There was a wide variation in both the interventions and study design. It is therefore hard to draw any conclusions from the data, except that the studies overall show that in general the proposed programmes are feasible and acceptable to parents, indicating an appetite and need for such programmes.

Whilst the interventions were varied in design, they did commonly work through groups. However, the scope of the study design was often limited, with only a narrow set of outcomes measured. It would be useful to have a wider range of child, caregiver, and family level outcomes captured, in line with the ICF, which has been similarly argued by Yousafzai (2014) and Rosenbaum (2011). Another gap is the need for a better understanding of change mechanisms. Whilst parent satisfaction with interventions is often high, it is often less clear how that then translates into improved outcomes for both the parent and child. This PhD aims to address some of these gaps, by understanding the impact of the training on both the child and caregiver (**Chapters five, six, seven**). It will also explore the role of caregiver empowerment and stigma in caregiver lives (**Chapters eight, nine**) and the

implications for the success of a caregiver/parenting programme for children with disabilities in the Ghana context.

Chapter Three Details of the parent training programme

Photo 1 Parent support group at one of the eight sites

Overview

In this chapter I briefly summarise the process of development of the parent training programme. I also summarise the content of the programme and the underpinning theoretical base.

The development process for the parent training programme

The plans to develop a parent training programme were a key recommendation following a large-scale survey of childhood disability in Bangladesh, undertaken in 2013. This survey estimated a prevalence of 0.9% of moderate or severe impairments (including physical, hearing, visual impairments and epilepsy) among children less than 18 years of age (Murthy et al., 2014). Despite cerebral palsy accounting for more than a third of moderate and severe childhood disability (3.7 per 1000), rehabilitative services available for these children were extremely limited in the area. Even where there were services made available to the families, the uptake of referrals was extremely poor (Bedford et al., 2013). Responding to this, the International Centre for Evidence in Disability committed to the development of a participatory community-based caregiver training package for children with cerebral palsy, which would be delivered through parent support groups. This development processes pre-dated this thesis, and therefore is not examined here in detail, but I provide a brief summary here of the process.

This process started with a review of already available training materials for parents in LMICs upon which to build this caregiver training programme. Criteria for the selection of suitable training material were identified at the outset, in conjunction with an advisory group, and included:

- ✓ An approach targeted at parents, using a parent support group model
- ✓ Materials which had been developed for working in a LMIC and were easy to use.

Based on these criteria, '*Getting to Know Cerebral Palsy*', a training package from South Africa (Cerebral Palsy Association, 2008), was selected as the core approach upon which to base this programme. Our aim was to further develop and modify the approach, building on

a range of other relevant resources, including input from experts, and strengthening the participatory approach which we wanted to underpin the intervention.

In agreement with the authors of the original *'Getting to Know Cerebral Palsy,* the training material was further developed and revised through an action research process in Bangladesh, over an 18-month period, from September 2011 to February 2013. The research was undertaken in two sub-districts of the Sirajganj district, where a total of 14 parent groups were established in a phased approach over a one-year time period. The development process was complemented by two stages of reviewing the manual, with a multi-disciplinary advisory team of practitioners (occupational therapists, physiotherapists, speech and language therapists, community health workers) and researchers. I led on the final revisions and development of the training material with this team.

The resulting product was an adapted version of *'Getting to Know Cerebral Palsy'* launched in May 2013 (LSHTM and Hambisela, 2013). The overall aim was to be *'empowering to parents/caregivers*' in providing care and support for children with cerebral palsy. From this point in the thesis, I will refer to the training programme as 'GTKCP'. A copy of the programme and resources are available at https://www.ubuntu-hub.org/

The following two publications (completed prior to this PhD) document learning from the GTKCP development process and are available in Appendices Part 2 Supplementary papers.

- Zuurmond, M., Mahmud, I. & Hartley, S. 2018. Children with cerebral palsy in Bangladesh: Their contribution to the development of a rehabilitation training programme. *Disability, CBR and Inclusive Development,* 29**,** 25-42.
- Zuurmond, M., Mahmud, I., Polack, S. & Evans, J. 2015. Understanding the Lives of Caregivers of Children with Cerebral Palsy in rural Bangladesh: Use of Mixed Methods. *Disability, CBR & Inclusive Development,* 26**,** 5-21

Description of the overall programme

The overall programme consists of a number of components:

- ☐ **Training programme:** The main focus of the programme is training delivered though a support group of ideally eight-10 caregivers, based at a community level. The training is ideally conducted in a venue which is identified as suitable and accessible by the caregivers themselves. GTKCP consists of 10-modules (see Figure 2 Overview of modules delivered to caregiver groups established in a community setting.
- ☐ **Home Visit**: A second component is a monthly home visit of, on average, one hour, conducted by a group facilitator. The main aim of the monthly home visit is to engage with other family members and to provide follow up support to the primary caregiver within the home context. It is recognised that other family members play a key role in the care of the child and/or can act as gatekeepers, and the aim is for the home-visit to facilitate a greater dialogue within the home environment. Simple parental handouts were also designed to expedite this dialogue.

Figure 2 Overview of modules

- ☐ **Family and community sensitisation**: At the time of recruiting families, a sensitisation meeting is also conducted in each home to ensure that the caregiver has family support, and that they attend the meetings. An additional community sensitisation meeting is also organised for each home community to briefly explain the purpose of the support groups.
- ☐ **Group Facilitators:** Ideally the programme is delivered by a pair of facilitators, including a therapist (for example, physiotherapist, physiotherapy assistant, occupational therapist, speech and language therapist) a primary health care or CBR worker, whichever is most relevant to the local setting.

A description of the programme modules

The caregiver programme consists of 10 modules that are delivered over 10-12-months[1], consisting of a once-a-month caregiver support group training of approximately three hours, and a monthly home visit. The participatory training programme covers different aspects of care and support including:

(1) An introduction to cerebral palsy

(2) Evaluating your child

(3) Positioning and carrying

(4) Communication

(5) Everyday activities

(6) Eating and drinking

(7) Play

(8) Disability in your local community

(9) Running your own parent support group

(10) Assistive devices and resources.

Details of each module is provided in *Table 4: Overview of training modules*

[1] There are 10 modules, but a couple of the modules are sometimes delivered over two sessions.

Table 4: Overview of training modules

Module	Overview
Module 0: Before You Begin!	This module aims to help you plan for your training. It also provides some useful tools for monitoring and evaluation.
Module 1: Introduction	This provides an introduction to the whole training course, and an introductory session about cerebral palsy.
Module 2: Evaluating Your Child	This helps parents to understand where their child is in terms of development, and setting of some suitable short term goals to achieve. It also provides some basic information about epilepsy.
Module 3: Positioning and Carrying	This provides practical advice to help caregivers to understand the importance of correct positioning and carrying.
Module 4: Communication	This session explores what communication is, why it is so important, and gives practical advice about what you can do to help your child communicate.
Module 5: Everyday Activities	This looks at how to use everyday activities to help your child with cerebral palsy to develop.
Module 6: Feeding Your Child	This is a long module focusing on feeding practices and challenges, and at least 3 sessions is recommended, including a final practical session.
Module 7: Play	This looks at some simple ideas of how parents/caregivers can encourage their child to play using simple local resources and introduces challenges around inclusion in play in the community. There is a third recommended practical session in making toys.
Module 8: Disability in Your Local Community.	This provides basic information on the rights of persons with disabilities and explores some of the main barriers to inclusion of disabled children in the community and the ways these might be addressed.
Module 9: Running Your Own Parent Support Group	This session looks at the value of setting up or continuing parent support groups in your local community, the value of networking, and some top tips for parents/caregivers around how to get the most out of running a group.
Module 10: Assistive Devices and Resources	This provides some useful information about providing assistive devices in poorer resource settings. It also details available resources and materials.

The underpinning approach of the programme

The foundations for the development and adaptation of the training programme were principally underpinned by a participatory rural appraisal (PRA) approach (Chambers, 1994b), and also elements of adult learning theory (Knowles et al., 2005, Cox, 2015).

The PRA approach draws from the work of the educationalist Paulo Freire, and his emphasis on social transformation through *conscientisation* of the individual (Freire, 1996). The PRA family of approaches promoted by, amongst others, Robert Chambers (1994a, 1994b), has several basic elements. Firstly, it is about using participatory methods to facilitate analysis of life issues, using approaches which are accessible and can promote engagement. Secondly, a shift in the attitude of the facilitator or 'outsider', so that they '*step off their pedestals, sit down, "hand over the stick," and listen and learn',* essentially with learning taking place in the field as opposed to a classroom, and taking a bottom-up approach (Chambers, 1994b p.1438). A third element of the philosophy is the importance of sharing both knowledge and experience, as a result of the sharing of their own reality, and ultimately about their sense of empowerment as part of that process. PRA has also been successfully as an approach used with women's groups to improve maternal and child health (Tripathy et al., 2010, Morrison et al., 2010).

A similar emphasis on the importance of participant engagement, and of experiential learning, is core to Adult Learning Theory (Knowles et al., 2005, Cox, 2015). There are several key underpinning principles of adult learning including that it should be: problem centred, have immediate relevance to their lives, utilise practical application and practise,

recognises that adults have a wealth of life experience which can help or hinder learning, and that adults should be involved in the planning and evaluation of the learning. Elements of this theory informed the programme approach in several ways: in our approach to training facilitators in how to facilitate the training sessions, and in training content which emphasises caregiver experience sharing and using that as a stepping stone for problem solving, combined with opportunities to practise new skills in a safe environment. I return to these theories in the final **Chapter ten**, where I briefly reflect on lessons learnt on their relevance, based on learning from the programme.

Having further developed and refined the programme in Bangladesh through a process of action research, the next step was to assess the impact of the approach. Ghana was selected as the target country by the funder, CBM International, as they were running a community based inclusive development programme in-country.

Adapting the training to the Ghanaian context

The GTKCP training material is inherently flexible, encouraging facilitators to use their own case study material to reflect the local context. Several steps were taken to adapt GTKCP to suit the Ghana context. The material was reviewed by both the national advisory group members, and also by the Ghana Federation of Disability Organisations (GFD). During the facilitator training (see **Chapter four** Methodology for details on this), there was an opportunity for feedback and review, particularly of case study material, so that it could be adapted for local relevance. Following the collection of the baseline survey data (see **Chapter five**) for this research project, there was also an opportunity to make changes to

ensure the training package reflected the local context. For example, as a result of the high level of malnutrition identified in the baseline survey, the module on ‘Feeding’ was introduced earlier in the training, and referral processes for nutrition services were additionally strengthened. Finally, a mid-term review meeting, and ongoing discussion of the materials on WhatsApp by the lead project coordinator, ensured ongoing reflection and informed further small adaptations needed.

Chapter Four Methodology

Photo 2 Training of facilitators workshop April 2015

Overview

In this chapter I describe the methodology of the impact study in Ghana, which is the site from which the data used in this thesis are drawn. This includes details of the overall research design, the theory of change, the research paradigm, and the tools.

Overall Study Design

This was a longitudinal mixed methods study, using a pre-post evaluation design. The rationale for this design was based on a number of factors. In the first place we wanted a 'proof of concept' for the approach, to assess its feasibility in a low-resource setting and assess whether there is impact, as well as illuminating the underlying processes of caregiver engagement.

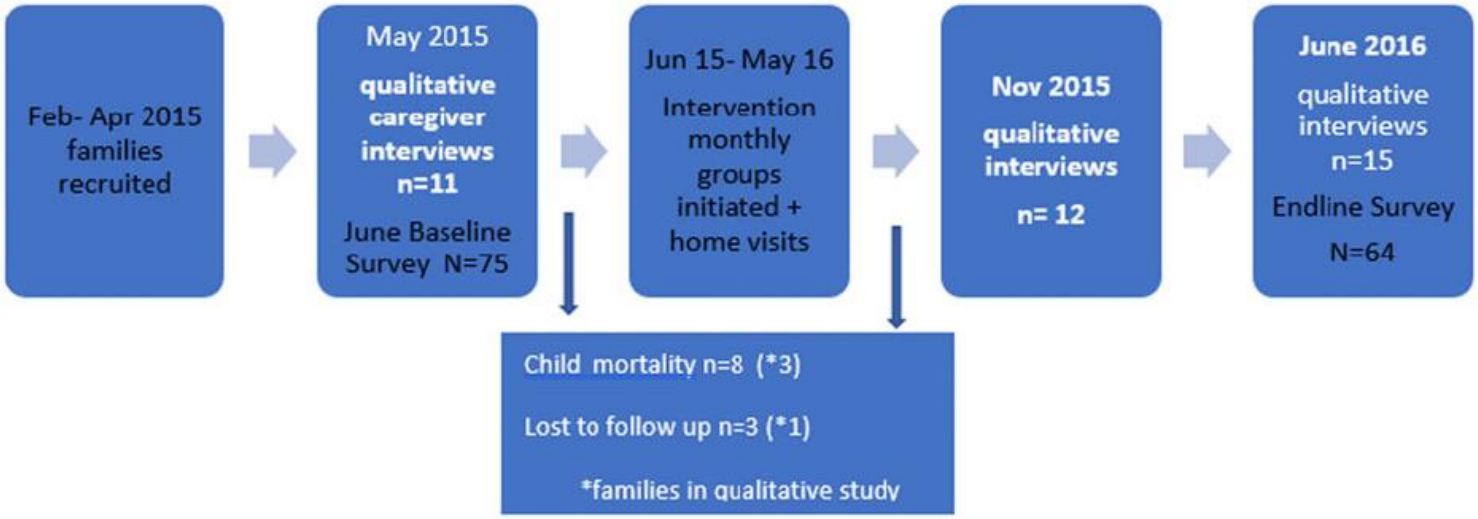
A cluster-RCT was not the design adopted for several reasons. Firstly, it was considered too early a stage in the testing of the programme and secondly, for a cluster-RCT to be sufficiently powered it would have required substantial numbers of children and caregivers which were not available to the project within the time frame and funding available. Finally, there were ethical considerations of offering a support package to some families, and delaying support to others, especially given the accepted evidence for the importance of early intervention for children with developmental disabilities.

In summary there were two components to the study design which included:

- A cross-sectional quantitative survey conducted with programme participants at baseline (prior to the training programme) and endline (after the training programme) with all children and caregivers
- Longitudinal qualitative research with families engaged in the training programme over a six to 15 month period

The use of mixed methods and combining of multiple data sources for evaluation is a well-established approach, offering the opportunity to address different aspects of the same

research question (Green and Thorogood, 2009). This approach is also in line with UK Medical Research Council guidelines for evaluating complex interventions, defined as interventions that have several interacting components (Craig et al., 2008). These same guidelines recommend developing a Theory of Change as part of the research design



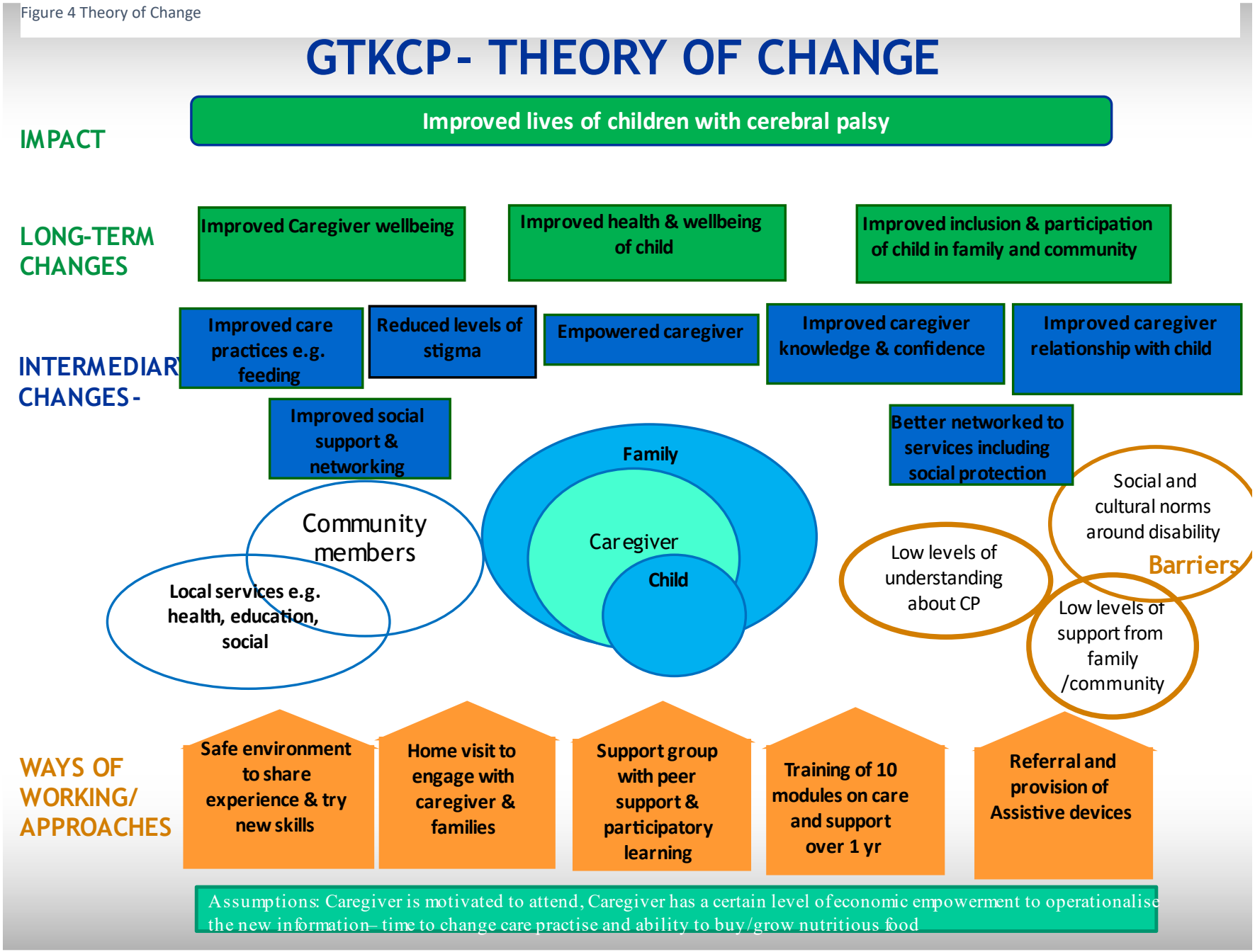
process (Campbell et al., 2000, Craig et al., 2008).

Figure 3 Flow chart showing the research process

Theory of Change

A Theory of Change (ToC) details key ingredients and pathways of change within a programme, underlying assumptions, and contextual issues. It fills in the 'missing middle' between what a program does (its activities) and how these lead to desired goals being achieved (De Silva et al., 2014).

Figure 4 Theory of Change



The ToC for the caregiver programme drew upon various elements: 1) the caregiver literature, 2) earlier work by our team in Bangladesh (Zuurmond et al., 2015), 3) adult learning theory and the value of participatory approach which underpinned the training (Knowles, 1984, Chambers, 1994a, Chambers, 1983) 4) the ICF model of disability and 5) ecological systems theory. See Figure 4.

The ToC was informed by the ICF in several ways. Firstly, there is training content which aims to mitigate the impact of cerebral palsy on bodily functions and promote engagement in everyday activities, emphasising opportunities for improved participation. For example, a module to improve positioning of the child to help the child's development and improve feeding practices. It also provides the opportunity for the child to be part of everyday activities in the household, for example, in a well-supported position they are better able to play, with increased opportunities to engage with siblings.

Another alignment with the ICF is the attention paid to factors in the child's (and caregiver's) environment. The use of a support group approach for the caregiver, combined with home visits to engage other family members, builds on the understanding that services need to be family-centred, and address the isolation of the caregivers. The importance of the family environment is reflected in the choice of caregiver wellbeing as a primary outcome in evaluating this programme, which is detailed later in this chapter. The bi-directional nature of these inter-relationships is also illustrated. For example, in feeding and drinking practices, the expectation is that the training will lead to changes in caregiver feeding skills, resulting in improved child-level anthropometric outcomes, and in turn, this will ease the caregiver

stress commonly faced at mealtimes. The home visit component is also intended to address environmental issues, specifically family engagement in caregiving, and to address negative attitudes towards disability, as well as broader opportunities for community engagement.

Caregiver empowerment is considered both a process and outcome within the proposed ToC. There are a variety of conceptual models of empowerment, and these are explored in more detail in **Paper 3, Chapter eight**. In summary, this thesis draws mainly upon the dialogue on empowerment in the gender and development literature that explores the different dimensions of power (Moser, 1989, Rowlands, 1997). This in turn builds upon the work of Paulo Freire and the international development literature on poverty reduction (Chambers, 1994b, Freire, 1996) which underpins the PRA training approach as previously outlined in **Chapter three** (Section on the Underpinning approach). In the literature review (**Chapter two**). I also highlighted the limited literature on caregivers and empowerment in the context of the child with a disability and is a process that needs to be better understood in caregiver programmes.

The ToC proposed pathways of change indicate that the caregiver will gain improved knowledge and confidence, and consequently be able to effect changes in her own practice. The support group model will offer social support outside of the family to address issues of isolation, and opportunities for problem solving and shared experiential learning. One key proposed pathway is that the 'empowered' caregiver will transfer knowledge and skills into the family, as well as with other community members. With improved understanding of their rights to services, the caregiver will have agency to access services for their child

including health services, and/or social protection such as the Disability Common Fund, and/or education, as relevant. However, there are some assumptions being made here about the nature and pivotal role of caregiver empowerment which will be explored in **Chapter eight**.

The ToC also lightly drew upon Bronfenbrenner's ecological theory (Eriksson et al., 2018, Bronfenbrenner, 1992, Bronfenbrenner, 1994b) which explores child development within the context of a layered environment; with interactions within one layer, and also between layers which impact on the child's development. All interactions are bi-directional, both within an ecological layer, and across them. For example, a child will be influenced by people in their environment and will also be capable of changing the beliefs of others. The immediate layer around the child, the microsystem, is considered the most important, and crucial for the child's development. The second, the mesosystem layer, describes interactions between these microsystems. The third layer, the exosystem, has indirect impact on the child, and includes broader factors within community life and/or extended family, and media. The macro-system includes social and cultural norms, religious beliefs, and laws, for example cultural beliefs that mothers are responsible for child-rearing, or related to beliefs about disability. Finally, a chronosystem which considers changes over time in relation to the child's environment, for example how the interaction and importance of different layers may change as the child becomes older. Bronfenbrenner's theory evolved over time, and a later revision was called a 'Bioecological' model, to reflect more strongly the role of biological processes in the child's development. His conceptual model has been adapted extensively and used in guiding many public health interventions, beyond childhood development (UNICEF, 2015, McLeroy et al., 1988, Eriksson et al., 2018).

In this thesis, the aim is to better understand how various factors and dynamics within the socio-ecological system interact with the training programme and the caregiver experience. I refer to the terms socio-ecological system and caregiver ecosystem interchangeably.

Finally, within the ToC, some of the key barriers identified include social and cultural norms towards disability, isolation, lack of support from the family and community, and limited local services. However, it was important to understand how these factors might impact upon the programme process and outcomes. It was also assumed that that poverty levels would not impede caregivers' engagement in the support group. These barriers and assumptions are explored in the results (**Chapters five** to **nine**) and also in the final **Chapter ten**.

Research paradigm

Whilst I wanted to understand and measure whether there was an impact of the intervention in terms of caregiver QoL and various child-level measures, I also wanted to answer questions of the 'what', 'how', and 'why' of any change. This exploration of experiences and processes is best suited to the use of qualitative methods (Green and Thorogood, 2009). This use of different methods reflects balancing both a positivist philosophy and an interpretive approach in my epistemological viewpoint (Green and Thorogood, 2009, Creswell, 2013), depending on the type of information that we are aiming to 'measure' and understand.

The positivist philosophy assumes there is a stable reality out there which can be measurable and observable (Green and Thorogood, 2009), For example, some of the outcomes assessed through the survey, such as the anthropometric measures on the child, provided objectively 'measurable' data on the levels of malnutrition.

The impact of this programme, however, depends on changes in human behaviour within an ecosystem of different relationships and complex societal norms. This is best captured through an interpretive approach which allows us to focus on people's own interpretation of their world. For example, in our study we are interested in capturing how caregivers perceive their lives and their children's lives, and how they relate to the training and support groups. The interpretive tradition adopted in this thesis for the qualitative work is rooted in a constructivist view of the world, that there is no single reality, but instead there are mutiple dimensions to a given phenomena (Creswell and Creswell, 2017, Kielman et al.,

2012). People's worlds are not objectively and passively experienced, but within a phenomenological philosophy are subjectively understood and *'created through talk, interaction and behaviour'* (Green and Thorogood, 2009p.14).

A primary outcome measure for assessing the impact of the intervention is caregiver QoL. In accepting that QoL is a broad, complex, and multi-dimensional concept, the inclusion of qualitative methods, alongside quantitative approaches, are considered essential for gaining a more holistic and contextual understanding of people's lives, and for investigating culture, location, and social-group specific dimensions of wellbeing (Camfield et al., 2009, Young Lives, 2008, Gough and McGregor, 2007).

Embedded within the qualitative component, I also selected some participatory research tools to use in order to facilitate caregiver engagement in the research process, as well as to capture different dimensions of their experience (Chambers, 1994b). This decision was informed by the desire to see the research as a more cooperative emancipatory process, with the knowledge generated through the research being seen as an outcome of a process of sharing, reflection and experience (Wallerstein and Bernstein, 1988). An appreciative enquiry 'lens' was used to shape the approach to the interviews. Appreciative enquiry, normally used as an approach to evaluating organisational change (Hammond, 2013), has also been applied to work with individuals (Howard, 2013), and within action research (Coghlan and Brydon-Miller, 2014). This approach places more emphasis on exploring what is working well and why, with a focus on the positives and facilitating factors rather than on drawing out, and over-emphasising the problems. For example, one of the key underlying

principles of appreciative enquiry is understanding that communication and language is at the centre of our ability to change and that our words create the world we live in, which fits into an interpretivist research paradigm. Through the research process, in alignment with the underpinning programme aim of caregiver empowerment, I wanted to facilitate caregivers to reflect on what worked, or things they had done or seen others do which made the situation better, to also see if they could be part of the solution. Finally, I selected to use Case Studies in **Chapter eight, Paper 3**, to better explore the nature of the empowerment journey. The rational for the choice of case studies is detailed below.

Qualitative longitudinal research design

For the qualitative research, I selected to use a longitudinal design and conduct in-depth interviews with selected families up to three times over a 15-month period. A strong argument for a longitudinal approach is that it captures a 'movie' rather than simply a 'snapshot' of social life (Berthoud, 2000), and is therefore an approach which is better suited for grasping the complexity of change over time, and to appreciate the interaction of personal, social and structural issues on the lives of individuals (Neale and Flowerdew, 2003, Young Lives, August 2008), which arguably is well suited for exploring different layers of the child and caregiver socio-ecological ecosystem and the interactions both within and across layers.

In-depth face to face interviews were chosen to enable probing for more personal and sensitive information, especially around issues such as stigma. These enabled more tailoring of the probes and were also suited to collecting data in the caregiver home, with the focus on understanding change at the individual level as a result of the training.

The choice to use a selection of case studies, to complement the thematic analysis, was in order to enable greater richness, detail, and completeness, in comparison than with other analytical approaches, (Flyvbjerg 2013, Prior 2016). It would enable a better illumination of the influence of the dynamic relational, social, and economic dimensions over time, which is not always captured so clearly by presenting a thematic analysis based on data collected at one time point. This was felt to be valuable for better understanding the nature of an empowerment 'journey' for the caregivers.

Reflexivity and my role

As the lead researcher on developing the training programme and in the design and implementation of the research, it is important to be reflexive about how I inevitably shaped the data generated. Reflexivity is an extension of the interpretive tradition, whereby the researcher must be critically reflective about their role in the research process and potential influence upon it, and how this contributes to the production of knowledge. It involves reflection on self, process, and representation, and should examine power relations in the research process as well as the interpretation (Green and Thorogood, 2009, Sultana, 2007, Darawsheh and Stanley, 2014, Jones, 1997). I did not sit by and observe the world objectively, but in the same way as those researched, I am also influenced, and in turn influence, through my own positionality (England, 1994).

I am a 53-year-old white British female, with 28 years of experience of working in LMIC settings. Firstly, as a volunteer, then as a teacher, community worker and then researcher. I am also a mother. My educational background is in teaching and health promotion, and

qualitative research. I am not a medical/rehabilitation therapist, and so never approached the children and families in the study from the medical perspective of trying to understand what was 'wrong' with the child which needed to be 'fixed'. This perhaps meant that I took a more holistic view of the lives of families, which was a thread from the design stage through to field work.

Obviously, this is not necessarily how caregivers and other family members viewed me, and there were certainly times in the field work where I was seen as the '*white doctor'* who might have a cure for their child. At least one benefit of the longitudinal nature of this research is that it allowed me to build up relationships with some of the families over time, and some level of trust and improved understanding on their part about the purpose of the interviews. It meant I was able to move the interview beyond the common response that everything is 'fine'. I think that, combined with the women's experience of the support group intervention, the interviewees were also able to see that they had something to contribute through the research process to the overall improvement of the programme.

A key challenge for me, especially during the first interviews, was that the interviews could be harrowing. In almost all of our first interviews the women were in tears as they recounted their stories, and many of these are still etched in my memory. Drawing on my own life experience, I felt that being able to sit on the floor with the mothers and grandmothers, using my body language, and words of support (even if translated) at times of distress, were essential for conveying some level of empathy with their experience, even if I was still seen as an 'outsider'. I believe that being an older female researcher was

probably helpful in that space. As almost every caregiver was female, I think it did help that I was a female researcher, and this may have encouraged the female interviewees to be more open. Holding a baby and/or interacting with a child on arrival at the home were also important elements of building a rapport, as well as offering a powerful message to a caregiver of acceptance and inclusion. This may have been easier for me as a female researcher, and more acceptable to the interviewees. Knowing when to pause and allow for tears was important, and it also meant that at times there was a need to be careful and not step over the line from being a researcher to taking on a counselling and advisory role. That said, when the interviews were completed, we invested time with the mother to offer some brief reassurance about the follow up through the intervention. It was also a time to check on any safeguarding issues, not only for the child but also for the mother, and to ensure linkages and referrals were made back to the team, as necessary. It may also have been that as an 'outsider' I was not seen as part of the problem, which may have offered me a more privileged position, at times.

Although this reflexivity around my role is important, it is important to emphasise that I was not working on my own. The role of the interpreter in the interview process as the interface between me and those being interviewed was also clearly influential. I will not explore that role in much detail here, but I agree that it is worthy of attention (Berman and Tyyskä, 2011). I worked closely with the local interpreter, an older female community worker, whose warmth and rapport with the families, especially the mothers and grandmothers, clearly had some impact on the interviews. My reflection is that she facilitated an environment which enabled the mothers to feel more comfortable in sharing their

experiences. After every interview I sat with the interpreter and we took time out to deconstruct what was said and not said and gather additional observations and local information to help enrich and inform some of the key emerging themes. I was also supported in the field by a Ghanaian researcher who led on interviews in some sites. She was also an older and experienced researcher, with a background in physiotherapy. We regularly discussed all of the interviews, and reflected on the key findings, in order to constantly review and reflect on perspectives and interpretations of what was being both said and observed. This data were collected in my field notes.

Ethics

Ethical approval was obtained from the London School of Hygiene & Tropical Medicine and from the Noguchi Memorial Institute for Medical Research, College of Health Sciences, University of Ghana (see Appendix 4: LSHTM Ethical Approval and Appendix 8: Baseline survey questionnaire).

A written information sheet was provided to the families, with a parent and child version. These were translated, and also read to families by the local CBR worker or CBID member of CBM International staff, with an opportunity for questioning about the programme. Written consent was then obtained from all participating caregivers, with a signature or thumbprint as appropriate. This consent also included permission for photos to be taken for the purposes of the research. All caregivers were then offered the support groups.

We worked closely with the national implementing partner, the Presbyterian Church of Ghana (PCG), and also with Christian Blind Mission (CBM) Ghana office who supported and funded the research, to ensure that referral pathways and support processes would be in place. All the sites were selected based on where PCG had their own programme and therefore had staff and structures in place, to provide additional support. PCG generally works in some of the poorest areas of Ghana, and so it was this essential to ensure additional support measures could be in place, if required.

Local services were mapped out by project teams as part of the process of establishing the groups. For example, following the high levels of malnutrition at baseline, referrals were established to local nutritional services.

In terms of the safeguarding and protection of vulnerable adults and children, the policies of both CBM International and PCG were included in training and adhered to.

Project location

The parent training programme was implemented in eight sites across Ghana. This included three parent training groups as part of a CBR programme in the north of Ghana, and five groups as part of an inclusive primary health care programme. The coordination and

establishment of all groups was supported by the PCG. Five regions were included: four groups in the Upper East region and four groups in Greater Accra, Brong-Ahafo, and the Ashanti region. See Figure 5.

Figure 5 Map to show areas where the programme was implemented

Participants for the study were recruited from across eight districts and four regions (Upper East, Greater Accra, Brong-Ahafo, Ashanti) in Ghana. Sites were selected by the project implementation partner (the PCG) because of their existing primary health care or community-based programmes, which allowed for onward referral of children in the study to other services, such as accessing assistive devices.

Study sample for quantitative study

The study aimed to recruit 80-100 children for the training. It was calculated that a sample size of 100 children with cerebral palsy would provide 80% power to detect an improvement in mean family-related QoL of 30% with an alpha of 0.05. The estimated improvement in QoL scores was based on data from the study in Bangladesh where the mean total *PedsQL™* (Paediatric Quality of Life Inventory) score was 52.4 (out of 100) in the families with a child with cerebral palsy and 79.8 in the families without a child with cerebral palsy. We considered it reasonable, based on the very low baseline caregiver QoL in the Bangladesh study (Zuurmond et al., 2015) and other data from Uganda on the impact of the training on parents (Motivation, 2014), for there to be at least a 30% improvement in the QoL over a 12-month period.

Children and families were recruited through existing CBR screening programmes for cerebral palsy and from hospital records from the primary health care sites, with some additional case finding in the target areas during April and May 2015. Inclusion criteria included children of 18 months to 12 years, children with all levels of severity of cerebral palsy, and where caregivers were not members of an existing parent support group. This age range was selected because the training programme is targeted at this age group, and

early diagnosis of cerebral palsy in children under 18 months can be difficult. All children included in the study had a confirmed clinical diagnosis by a physiotherapist from Ghana and a paediatrician from LSHTM at baseline. In total, 75 parents were recruited to the study within the time frame. We did recruit more families, but at one site we found that all the children had been mis-diagnosed with cerebral palsy.

Caregivers were invited to a newly established local support group. In total, eight support groups were established, each with eight to 10 parents. The recruitment sites are based where the programme partners (PCG) have existing CBR / inclusive primary health care programmes, in order that parent training could be supported through an existing structure, to facilitate referrals to assistive devices, and enable on-going support to families beyond the study period. Although intended as a community-based programme, in some of the more rural areas, the families were quite dispersed, and some had to travel up to one hour to attend the group sessions. In Ghana this resulted in the groups being run in a range of venues; a community hall, a church, a school classroom, and a room offered by a local non-governmental organisation (NGO). The intention is that the sessions should *not* be held in a clinical setting, as it is intended to be a community-based programme, with a move away from a medical model of disability, and to be more easily accessible to families. The primary caregiver and child attended the training together. Transport costs were covered by the project.

Group Facilitators

The GTKCP programme was delivered by a pair of facilitators: a physiotherapist or physiotherapist assistant together with one primary health worker. In total 13 facilitators

were selected by the local partner. These consisted of 11 men and two women: one physiotherapist, four physio-assistants, one nutritionist, two CBR workers, one special needs teacher, two primary health care workers. These facilitators were identified by the local partner for the programme, and on reflection a better gender balance should have been a consideration.

Facilitator training and support

All facilitators for the programme underwent a one-week training course in Sandema, Northern Ghana run by a master trainer (SF), me (MZ), and CBM International colleagues, from 20th - 26th April 2015.

Photo 3 Master Training Northern Ghana

Fidelity of the training

The fidelity of the parent training approach was monitored using the following: one face-to-face visit to at least one training session, and a monthly phone call to each group facilitator. This was conducted by the project coordinator who was an experienced physiotherapist. The fidelity was subjectively assessed by the project coordinator, based on the observed adherence to the training manual instructions, during in the delivery process. A WhatsApp group was set up and used by facilitators for sharing their implementation experiences and enabled some further monitoring of the quality of delivery by the local project coordinator (SC). The initiative taken to establish the WhatsApp group was taken by the group facilitators themselves. Mid-way through the implementation of the programme, all facilitators met for a refresher and reflection meeting.

Data Collection and Tools

In line with the ICF and the ToC, and the aims of the study, the outcome measures were assessed at the level of both (1) the child, and (2) the caregiver. There was greater emphasis in this study in focusing on the outcomes on the caregiver. Whilst the caregiver QoL was a key outcome measure, the child QoL was not directly assessed due to the overall young average age of the child (3.8 years) and lack of suitable tools.

Survey

For the baseline and endline survey we used a structured questionnaire to collect data on all children and the primary caregiver included in the training programmes. The endline survey followed a similar format to the baseline survey. One data collection team visited all sites at

baseline, and a second data collection team visited all sites at endline. Key areas included in the survey were:

1) caregiver and family demographics
2) caregiver QoL (two measures)
3) knowledge and understanding about the condition
4) levels of confidence about caregiving

In terms of each child, the following was assessed:

1) level of severity of cerebral palsy
2) education of the child
3) Washington Group questions
4) health of the child including perceived health and questions on epilepsy
5) measures of difficulties with feeding and drinking and anthropometric measures

Data were collected electronically using a tablet (Google Nexus 7) and Open Data Kit (ODK) software. The same respondent (primary caregiver) was re-interviewed 13 months later, 1±2 months after completion of the last training session (endline).

Details of each tool in the survey

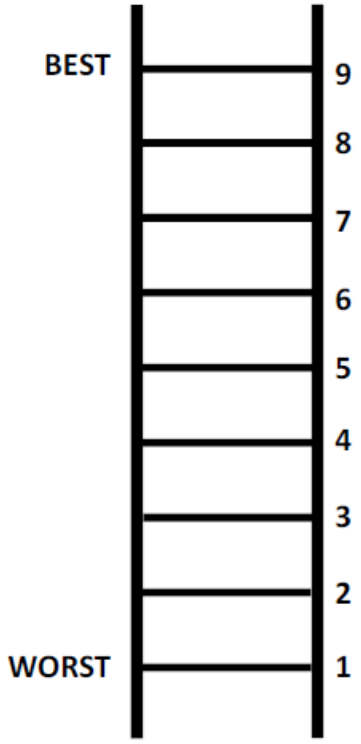
The primary outcome measure for the study was caregiver QoL. QoL was measured with the Paediatric QoL Family Impact Module (*PedsQL™).* This is designed to assess the impact of paediatric chronic health conditions on caregivers and the families. It measures caregiver self-reported physical, emotional, social, and cognitive functioning, communication, and worry, and impact of caregiving on family daily activities and family relationships (Varni et al., 2004). It has been developed and validated in a high-income setting but has also been used in some LMIC settings (Zuurmond et al., 2015) although not previously in Ghana. The *PedsQL™ Family Impact* was selected after a review of key QoL tools used commonly in caregiver and health research and selected for a number of reasons which included:

- Use in a previous project on the QoL of caregivers with a child with a disability in Bangladesh (Zuurmond et al., 2015)
- Simplicity and brevity of the questionnaire tool and thus practicality for translation into three languages
- Is designed specifically for caregivers with a child with a chronic complex health condition
- It explores the impact on the caregiver, and on the family, and domains assessed include family communication and relationships. This aligns with the project ToC, which proposed that there would be improved social support and communication about their child's impairment.

'Ladder of life' quality of life.

A 'Ladder of life' QoL (LoL-QoL) tool was also used to provide one simple measure of QoL.

The ladder was printed onto card; '0' being the first rung of the ladder and the worst possible life, and '9' being the top of the ladder and the best possible life. Interviewees were asked to state what would improve their QoL and what would worsen their QoL. This open text response was captured by the data collector, summarised into 1-2 key reasons. This tool was adapted from the Young Lives longitudinal study on childhood poverty (Crivello et al., 2009, Den Besten et al., 2016) and originates from the Cantril ladder (Cantril, 1965).



The results from this pilot are described in **Chapter six**.

Child and Adolescent Scale of Participation measure of child participation

At the planning stage of this study, in line with the ICF, I wanted to include a measure of child participation and selected the Child and Adolescent Scale of Participation (McDougall et al., 2013). This was adapted for the Ghana context, in advance of the field work, in discussion with national research staff and with permission of the author. However, during the piloting phase, it was decided to remove this measure for three reasons. Firstly, it became apparent that it would require considerable additional adaptation and time spent on modifying and re-testing, and only limited time was available for this. Secondly the baseline questionnaire was already very lengthy, averaging more than two hours to conduct per family, and there were concerns about response burden. Thirdly, considering the young age of the children, we would have to be reliant on proxy measures from the caregiver. This has a number of limitations including the evidence that there is less observable agreement between parents and children on emotional and social aspects of QoL (Eiser and Morse, 2001). Therefore, a decision was taken to remove this measure.

Gross Motor Function Classification System (GMFCS)

Severity of cerebral palsy was assessed using the Gross Motor Function Classification System (GMFCS) (Wood and Rosenbaum, 2000), an internationally-recognised system which classifies cerebral palsy according to five levels of physical functioning. This ranges from a 'level 1' classified as being able to perform gross motor skills including running and jumping, through to a 'level 5', where all areas of motor function are limited, and children have no means of independent mobility.

Health and Nutrition

Data on the child's feeding were collected using structured questions adapted from a previous study of children with cerebral palsy in Bangladesh (Adams et al., 2011). Eight questions were asked about frequency of difficulties with different aspects of eating and drinking, rated on a five-point scale from 'never' to 'always'. Reported health of the child was measured with three questions taken from the Ghana DHS (Demographic and Health Surveys) about whether their child has experienced diarrhoea, fever or cough in the last two weeks (Ghana Statistical Service, March 2015) and one question about experience of a serious health condition requiring hospital admission in the last 12 months.

Anthropometry

Anthropometric measures were taken using standardised protocols. Standing height was recorded to the nearest 0.1cm for children >5 years. Recumbent lengths were taken for children <5 years, where possible, and knee height (Froehlich-Grobe et al., 2011) was recorded for all children to the nearest 0.1cm. Following WHO best practice (World Health Organization and UNICEF, 2009), height and length measurements were obtained twice by two independent observers: the average was taken as the final measurement if they agreed to within <0.5cm. Or they were both re-measured until agreement was achieved. Mid Upper Arm Circumference (MUAC) was recorded for all children. Weight was recorded to the nearest 0.1kg. If children were unable to stand unaided, then the caregiver was weighed separately, and then asked to hold the child, and reweighed, in order to calculate the child's weight.

For full details of the questionnaires see Appendix 8: Baseline survey questionnaire and Appendix 9: Endline survey questionnaire

Data collection process

The research team for the baseline survey was led by a paediatrician (American) and senior physiotherapist (Ghanaian), with a local translator. One translator was used for all the sites in the South (male CBR worker) and one translator for the Upper East region (female CBR worker). At endline, the lead was a physiotherapist (Ghanaian) and local data collector identified by PCG. Again, one translator was used for all the sites in the South and one for all the sites in the Upper East. All the data collectors received up to two days of training.

I was in the UK for this research component and my role included downloading and reviewing the data from the ODK software, to monitor the data and lead on discussion on any changes required with the in-country team, especially during the piloting phase.

The baseline was collected approximately 1-2 months before the start of the training, as there was a staggered start across the different sites. The endline data collection was similarly collected 1-2 months after completion of the training.

All families were contacted by PCG in advance of the visit, and all the interviews and assessments took place in their home, with a couple of exceptions where the family attended a local health centre.

Translation of tools, cognitive testing and piloting

The tools were translated at each site by a local translator. Particular attention was given to a written translation of the *PedsQL*™ measure in accordance with the guidance to use this tool.

Linguistic validation of the *PedsQL*™was conducted in three languages Twi, Gruni, and Kusaal. This included a process of forward and back translations by linguistic experts and then further modification following cognitive field testing in the three sites. The Twi language is widely spoken in Ghana but there are diverse dialects: Akuapem Twi, Ashante Twi, Fante Twi and Bono Twi are both spoken and written forms. Kwahu and Akyem Twi are only oral dialects. Most people can understand all the six Twi dialects, and we had to ensure that the translation was understandable across all the sites where Twi was spoken. Gruni and Kusaal are spoken in the Upper East region of Ghana. This posed some challenges around translation and required considerable time to ensure conceptual equivalence of terms. This is strongly recommended when translating and adapting QoL tools to a new context (Bowden and Fox-Rushby, 2003).

For each language, one day of cognitive testing was then conducted with 2-3 families who lived in the same area but were not part of the sample for the programme. The caregivers were asked how clear the questions were and what they understood by them. Their responses were further checked, in line with the guidance from the *PedsQL*™. The reports from the cognitive testing had to be submitted to the Mapi Research Trust, alongside the translation, as a condition of use of the tool. An example cognitive report is provided in Appendix 7: PedsQL™ Family Impact version: Kusaal cognitive field-testing report.

Methodological reflections from the cognitive testing

During the cognitive testing process, it was found that the five-level response scale ('*Never, Almost Never, Sometimes, Often, Almost Always'*) was sometimes problematic, as there were no direct language translations for some of the choice categories. For example, although there is a word in Gruni for 'almost' it is a literal translation and is not commonly used for describing the frequency of something in more abstract terms. A common problem in all the languages was around assessing the *frequency* of a problem in relation to the *occurrence* of the situation. And when some of the questions were quite broad, such as '*it is hard to find time for social activities*', the response would often be 'what kinds of social activities?' We addressed this by providing example of 1-2 concrete examples that were agreed upon as suitable to the Ghana context. For example, in relation to 'social activities' we gave the examples of attending church and attending family meetings.

Another key area of learning was on the choice of field translator/research assistant. During the piloting, very high scores were reported for the *PedsQL™* responses. This reflected overall 'good' QoL. However, this contrasted to the qualitative data that had been collected, and which indicated overall very poor caregiver wellbeing. This contradiction in the data was discussed during the testing at the first test site, and it was decided to change the research assistant/translator who was male, relatively young, and well educated. The lead national Ghanaian team member expressed some concerns that, '*due to his tone and mannerisms the mothers were a bit intimidated by him'*, with the consequence that the mothers were '*closed up'* on the sensitive questions. On the second day of the piloting, the decision was taken to change the research assistant to an older man with a disability who was an experienced CBR worker and thus skilled at building a quick rapport with the families. The

result of this change was that the research team felt that the caregivers were observed to be more at ease during the interviews, and the *PedsQL™* scores lowered and were more aligned with the reality of the stories and tears which accompanied them.

Survey Analysis

The quantitative data analysis for the survey was conducted by another researcher, SP. The full details of the methods of analysis are included in **Paper 1 (Chapter five)**.

Qualitative longitudinal research component

Sampling

A mix of purposive and theoretical sampling was used for the selection of families for the qualitative longitudinal research. Initially the aim was to include both adult caregivers and children, but with the average age of the children being 3.8 years, the focus was shifted to interviews with caregivers only.

Initially fourteen families were selected to be visited at three points during the programme: (1) at baseline (two months before initiation of the training), (2) at five months into the training, and (3) within two months of the completion of the training. Criteria for inclusion were a geographic spread, different age bands of children (18 months-5 years, 6-12 years), and children of different sexes, and different levels of severity of cerebral palsy. Three families were interviewed once only at baseline, as their geographical area was not one of the final training sites, and a further three children died in the early stages of the intervention after the first interview.

In planning for the mid-term interviews I drew upon the concept of theoretical sampling to select additional families. Theoretical sampling is associated with grounded theory methodology. It is an iterative process of sampling, where a decision is made on the choice of data to collect next, in order to help in further development of the theory (Glaser and Strauss, 2009). Whilst I did not adopt a grounded theory approach in my own research, I did want to take a more iterative approach to selecting the sample, in order to better investigate some factors, following the initial baseline data analysis. In this study, the baseline data suggested that poverty appeared to play a much more pivotal role shaping caregiving practice than I had anticipated. I therefore wanted to select two additional families that were of higher economic status, in order to try and better understand how poverty shaped the caregiver's engagement with the training. Motivation to engage with the training was a key assumption in the ToC, which I felt also needed exploring, and thus at mid-line two additional families were included who were less active and sometimes missed sessions, in order to better understand challenges faced in their engagement.

Eleven families were selected in the first round, and following the death of three children, a further five families in the second round, and two more at endline. Interviews were conducted with a total of 18 primary caregivers; seven were interviewed three times, five interviewed twice, and six interviewed once. Although the focus was on the experience of the primary caregiver, our design also included a short (opportunistic) interview with a secondary caregiver, if they were present in the household at the time of the interviews. This person was identified by the primary caregiver as also having a caregiving role. The initial focus of this interview was to capture other perspectives at the household level, and

also to explore the degree to which the learning from the support group was shared at household level.

Data collection

In-depth interviews with caregivers were conducted before the start of the programme (April-May 2015), mid-way in the programme (Nov 2015), and 1-2 months after completion (June 2016). See *Figure 3 Flow chart showing the research process* for the flowchart of the research process. Interviews were conducted by a lead interviewer (MZ) with support from a local researcher, conducted in four local languages with translation into English. On average interviews lasted one hour and were audio-recorded and then transcribed into English.

All interviews were conducted in the home setting, with a couple of exceptions where the family attended a local health centre. Where possible, caregivers were interviewed on their own, although this was not always possible in the rural context, and it often meant interviewing them under the shade of a tree away from the house. This home visit enabled unstructured observation of the child and caregiver in the home setting, for example to observe where the child was placed within the house, and to use these observations to prompt for more detail of the lived experience of the child with the caregiver. For example, observing where the child was positioned in the home setting, such whether they were lying down in the corner of a room on their own, and relatively excluded from the rest of the family.

A brief child progress update was sought from the facilitator for the mid-term and final interviews, to help develop suitable probes tailored to each family. A copy of all interview guides is available in Appendix 10: Qualitative Interview Guides: Baseline, Mid-term, Endline.

Methodological reflections on the longitudinal qualitative research

Although I have considerable experience in conducting qualitative interviews, this was the first time I had conducted longitudinal research, returning to the same interviewees, in some cases up to three times. I observed a number of benefits of the longitudinal research design. With repeat interviews there was generally increased openness or willingness to share sensitive experiences and personal feelings. This is likely to have been in part due to the positive effect of the caregiver engagement in the programme, as well as increased trust in the members of the research team, and increased familiarity with the research component.

The inclusion of a short interview with a secondary caregiver was useful for providing a different perspective, especially on sensitive issues such as stigma, thereby providing a more holistic view of the family context. I found, for example, especially during first interviews, that some primary caregivers were not very forthcoming about their stigma-related experiences. Instead, it was sometimes a secondary caregiver, such as a husband or a grandmother, who provided more detail. For example, a grandmother talked openly about her grandson being called a '*spirit child*' by the community and how excluded they all felt, whilst in contrast the young mother did not appear to want to, or was unable to, talk about

such difficult issues. In another example, a mother who was also a health worker, focused only on seeking a medical diagnosis for her son, which she may have felt was more 'acceptable' to share with us. In contrast, her husband was open about traditional beliefs which fuelled the traditional treatment sought.

Analysis

For the qualitative in-depth Interviews two stages of the analysis were conducted. Firstly, a thematic analysis across all the interviews at each of the three phases of interviewing, guided by *a priori* themes from the ToC, and then an iterative process of developing and shaping more themes and sub-themes (Green and Thorogood, 2009, Creswell, 2013). All transcripts were read by the lead international researcher and national researcher, and key emerging themes/sub-themes were discussed at an early stage between the national researcher and international researcher, and also with my supervisory team. This iterative process informed the coding framework, which was further revised with a second stage, more detailed coding, managed with NVivo software. The second stage analysis of the same data was the development of a biographical case study for each caregiver, combining the interviews at each stage and enabling me to better understand change over time for each case. These case studies were shared with my supervisory team for further discussion about key themes and the dynamics of change over time.

The data included transcripts, as well as fieldnotes and project monitoring forms in order to provide a more holistic overview of their lives, in line with guidance for longitudinal qualitative data analysis (Green and Thorogood, 2009, Creswell, 2013).

I led the qualitative data analysis with all final coding (MZ), with ongoing discussion with the Ghana-based researcher (GN), and my supervisory team, where further clarity was required. Data were managed using NVivo 12 software.

In the next **Chapters five** to **nine** I present the results from the study.

In addition to the papers submitted for this thesis, two other papers published from the data, focused on malnutrition and feeding, in which I am the final author, are also included in Appendices Part 2 Supplementary papers.

- Polack, S., Adams, M., O'Banion, D., Baltussen, M., Asante, S., Kerac, M., Gladstone, M. & Zuurmond, M. 2018. Children with cerebral palsy in Ghana: malnutrition, feeding challenges, and caregiver quality of life. *Developmental Medicine & Child Neurology,* 60**,** 914-921.
- Donkor, C. M., Lee, J., Lelijveld, N., Adams, M., Baltussen, M. M., Nyante, G. G., Kerac, M., Polack, S. & Zuurmond, M. 2019. Improving nutritional status of children with Cerebral palsy: a qualitative study of caregiver experiences and community-based training in Ghana. *Food science & nutrition,* 7**,** 35-43.

Chapter Five (Paper 1) Evaluating the impact of a community-based parent training programme for children with cerebral palsy in Ghana

Photo 4 Mother explaining community mapping to her support group

In this chapter I describe the impact of the intervention on both the child and caregiver, from an analysis of the quantitative data from the study. This is in answer to Study Objective 1 '*To assess the impact of a caregiver training programme upon the lives of children with cerebral palsy and their caregivers in Ghana'*.

A primary long-term outcome within the ToC is understanding the impact of the programme on caregiver quality of life. This was assessed using both qualitative and quantitative approaches. In this paper I detail the results from the quantitative measures employed. This includes the PedsQL™ Family Impact measure, which assesses parent's self-reported physical,

emotional, social, and cognitive functioning, communication, and worry, as well as daily activities of the family, and family relationships. The paper also details changes in caregiver reported changes in knowledge and confidence as well as their care practices. In the latter, there is a focus on understanding reported changes in feeding practices, particularly in light of the high levels of malnutrition which are detailed at baseline.

A second long term outcome reported on in this paper is improvements in child 's health and wellbeing. This is assessed in several ways, detailed in the paper. One key indicator reported on is changes in levels of child malnutrition, combined with the parent reported changes in feeding and drinking practices. Parent reported measures of child health are also detailed. The paper summarises the study's family demographic data, for example, it details the high level of absent fathers from the household. This is useful in helping to appreciate the micro-system of the caregiver-child dyad in the local context.

My role is detailed in the publication including lead on development of the questionnaire, remote supervision of the data collection, writing and editing of the paper. Sarah Polack conducted all the statistical analysis for this paper.

LONDON SCHOOL of HYGIENE &TROPICAL MEDICINE

London School of Hygiene & Tropical Medicine
Keppel Street, London WC1E 7HT

T: +44 (0)20 7299 4646
F: +44 (0)20 7299 4656
www.lshtm.ac.uk

RESEARCH PAPER COVER SHEET

Please note that a cover sheet must be completed for each research paper included within a thesis.

SECTION A – Student Details

Student ID Number	461745	**Title**	Ms
First Name(s)	Maria Anne		
Surname/Family Name	Zuurmond		
Thesis Title	Understanding the lives of caregivers and evaluating a support programme for caregivers of children with disabilities: lessons learnt from Ghana		
Primary Supervisor	Janet Seeley		

If the Research Paper has previously been published please complete Section B, if not please move to Section C.

SECTION B – Paper already published

Where was the work published?	Plos One		
When was the work published?	Dec 12 2017		
If the work was published prior to registration for your research degree, give a brief rationale for its inclusion	No		
Have you retained the copyright for the work?*	**Yes**	Was the work subject to academic peer review?	**Yes**

*If yes, please attach evidence of retention. If no, or if the work is being included in its published format, please attach evidence of permission from the copyright holder (publisher or other author) to include this work.

SECTION C – Prepared for publication, but not yet published

Where is the work intended to be published?	
Please list the paper's authors in the intended authorship order:	

Stage of publication	Choose an item.

SECTION D – Multi-authored work

For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)	Conceptualisation, design, data curation, investigation, project administration, writing original draft and contribution to final editing

SECTION E

Student Signature	[redacted]
Date	08/12/2020

Supervisor Signature	[redacted]
Date	8th December 2020

PLOS ONE

RESEARCH ARTICLE

Evaluating the impact of a community-based parent training programme for children with cerebral palsy in Ghana

Maria Zuurmond[1], David O'Banion[2], Melissa Gladstone[3], Sandra Carsamar[4], Marko Kerac[5], Marjolein Baltussen[6], Cally J. Tann[7], Gifty Gyamah Nyante[8], Sarah Polack[1]*

1 International Centre for Evidence in Disability, London School of Hygiene and Tropical Medicine, London, United Kingdom, **2** School of Medicine, Emory University, Atlanta, Georgia, United States of America, **3** Institute of Translational Medicine, University of Liverpool, Liverpool, United Kingdom, **4** Physiotherapy Department, Korle Bu Teaching Hospital, Accra, Ghana, **5** Department of Population Health, London School of Hygiene and Tropical Medicine, London, United Kingdom, **6** CBM West Africa Regional Office, Accra, Ghana, **7** Department of Infectious Disease Epidemiology, London School of Hygiene and Tropical Medicine, London, United Kingdom, **8** Department of Applied Health, University of Ghana, Accra, Ghana

* sarah.polack@lshtm.ac.uk

Check for updates

OPEN ACCESS

Citation: Zuurmond M, O'Banion D, Gladstone M, Carsamar S, Kerac M, Baltussen M, et al. (2018) Evaluating the impact of a community-based parent training programme for children with cerebral palsy in Ghana. PLoS ONE 13(9): e0202096. https://doi.org/10.1371/journal.pone.0202096

Editor: Andrea Martinuzzi, IRCCS E. Medea, ITALY

Received: December 12, 2017

Accepted: July 22, 2018

Published: September 4, 2018

Copyright: © 2018 Zuurmond et al. This is an open access article distributed under the terms of the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

Data Availability Statement: The ethical approval of this study did not include clearance of data for public release, as the participant consent forms did not state that the information would be made fully available. Data are from the Evaluating the impact of a community based parent training programme for children with cerebral palsy in Ghana study, and the authors may be contacted at sarah.polack@lshtm.ac.uk or disabiltycentre@lshtm.ac.uk.

Abstract

Background

In low and middle-income settings, where access to support and rehabilitation services for children with disabilities are often lacking, the evidence base for community initiatives is limited. This study aimed to explore the impact of a community-based training programme for caregivers of children with cerebral palsy in Ghana.

Methods

A pre and post evaluation of an 11-month participatory training programme ("Getting to Know Cerebral Palsy") offered through a parent group model, was conducted. Eight community groups, consisting of a total of 75 caregivers and their children with cerebral palsy (aged 18 months-12 years), were enrolled from 8 districts across Ghana. Caregivers were interviewed at baseline, and again at 2 months after the completion of the programme, to assess: quality of life (PedsQL™ Family Impact Module); knowledge about their child's condition; child health indicators; feeding practices. Severity of cerebral palsy, reported illness, and anthropometric measurements were also assessed.

Results

Of the child-caregiver pairs, 64 (84%) were included in final analysis. There were significant improvements in caregiver quality of life score (QoL) (median total QoL 12.5 at baseline to 51.4 at endline, P<0.001). Caregivers reported significant improvements in knowledge and confidence in caring for their child (p<0.001), in some aspects of child feeding practices (p<0.001) and in their child's physical and emotional heath (p< 0.001). Actual frequency of reported serious illness over 12-months remained high (67%) among children, however, a small reduction in recent illness episodes (past 2 weeks) was seen (64% to 50% p < 0.05).

Funding: This research was supported by CBM International at http://www.cbm.org/. The funder had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.

Competing interests: The authors have declared that no competing interests exist.

Malnutrition was common at both time points; 63% and 65% of children were classified as underweight at baseline and endline respectively (p = 0.5).

Conclusion

Children with cerebral palsy have complex care and support needs which in low and middle-income settings need to be met by their family. This study demonstrates that a participatory training, delivered through the establishment of a local support group, with an emphasis on caregiver empowerment, resulted in improved caregiver QoL. Despite less effect on effect on child health and no clear effect on nutritional status, this alone is an important outcome. Whilst further development of these programmes would be helpful, and is underway, there is clear need for wider scale-up of an intervention which provides support to families.

Introduction

There are an estimated 150 million children globally living with a disability [1]. The vast majority (80%) of these children live in resource poor settings, where the rehabilitative services available are extremely limited [2]. Cerebral palsy, is the most common cause of physical impairment in children [3]: the prevalence is estimated to be 2–3.5 cases per 1000 live births [4] but is likely to be higher in low and middle-income countries (LMIC) [5]. Children with cerebral palsy often have multiple co-morbidities—including visual, hearing, and intellectual impairment, and epilepsy—requiring a multi-disciplinary approach to care and support over their lifetime [4]. They are more likely to experience poor health [2, 6] and have diverse rehabilitation needs, yet they often face a range of barriers in accessing health and education services [7, 8]. This contravenes the rights of children with disabilities to health care, education and social participation enshrined in the UN Convention on the Rights of Persons with Disabilities [9]. Further, the Sustainable Development Goals emphasise the importance of 'leaving no one behind' [10] and the Global Strategy for Women Children and Adolescent's health [11] demands a more transformative agenda, moving beyond just survival, for maternal child and adolescent health.

Evidence shows that caregivers of children with disabilities in low resource settings are more likely to experience stress, social isolation, emotional and physical impacts [12–15]. The scarcity or complete absence of rehabilitation services in LMICs can result in families providing the bulk of care for their child, often with little or no access to training and support. Specifically in the Ghana context, medical rehabilitation services have been described as being minimal [3, 16], with only an estimated 150 registered physiotherapists for a population of 28.2 million, and the first cohort of nationally trained occupational therapists only graduating in 2017 [17]. While there have been calls for community and home-based programmes to improve care and support, emphasising the central role of families [18], these are currently lacking, and there is a dearth of studies evaluating their impact on children and their caregivers [19–21].

In response to this recognised need for home and community-based interventions, the International Centre for Evidence in Disability (ICED) developed a participatory caregiver training package for children with cerebral palsy '*Getting to know cerebral palsy' (GTKCP)* [22], adapted from a training resource called Hambisela [23]. GTKCP aims to empower caregivers and to improve care and support for children, within a rights-based framework.

Fig 1. Modules of training programme.

https://doi.org/10.1371/journal.pone.0202096.g001

Using a participatory approach, a local parent support group was established, and they received monthly training sessions, consisting of 10 modules which are run over 11–12 sessions (Fig 1). The programme was developed through action research in Bangladesh [22] and has since been widely implemented across a variety of LMIC settings. However, empirical evidence is lacking on the impact of this programme on the children with cerebral palsy or their caregivers. Exploring this is important for identifying and informing improvements to the programme.

The aim of this study was to evaluate the impact of the GTKCP parent training programme on children with cerebral palsy and their caregivers in Ghana. Specifically, we aimed to explore the impact on caregiver quality of life and knowledge and attitudes towards caring for the child, and on the child's health and nutritional status.

Methodology

This study was a pre/post mixed-methods impact evaluation of the GTKCP parent training programme in Ghana. This article reports on the quantitative component of the study.

Project location and study participants

Participants were recruited from across eight districts and four regions (Upper East, Greater Accra, Brong Ahafo, Ashanti) in Ghana. Sites were selected by the project implementation partner (The Presbyterian Church of Ghana) because of their existing primary health care or community-based programmes, which allowed for onward referral of children in the study to other services, such as accessing assistive devices. A total of 75 children and their caregivers were newly recruited through existing community screening programmes for cerebral palsy, hospital physiotherapy records of children diagnosed with cerebral palsy in the last six months, and from additional community screening in one site.

Cerebral palsy was diagnosed by a qualified clinician (developmental paediatrician or physiotherapist). Eligibility criteria were: a confirmed diagnosis of cerebral palsy (of any type) and age 18 months-12 years. Children may have had some previous physiotherapy, but caregivers were excluded if they were already a member of a parent support group.

Intervention: Parent training programme

Caregivers were invited to a newly established local support group and offered a total of eleven once-a-month group training sessions each approximately three hours, in a nearby community setting. There were 8–10 parents per group. Although sessions were led by the facilitators, there was an emphasis on problem solving and peer support, underpinned by adult learning theory and an emphasis on participatory approaches to facilitate empowerment of the caregivers. Support groups were maintained following this training programme intervention, led by expert mothers, but this evaluation was conducted on completion of the initial training input following establishment of the groups.

The modular topics covered a range of issues as shown in Fig 1. In addition, all families were visited once per month by one/or both facilitators, for an average of 45 minutes, in order to provide one to one follow up support to the primary caregiver, and to discuss the training material with other family members.

The GTKCP programme was delivered by a pair of facilitators: a physiotherapist or physiotherapist assistant together with one primary health worker. A total of 13 facilitators underwent a one-week training from a master trainer and delivered to eight groups.

The fidelity of the training approach was monitored using the following: one face to face visit to at least one training session, and a monthly phone call to each group facilitator by the project coordinator and/or an experienced physiotherapist. A 'Whats App' group was set up and used by facilitators for sharing their implementation experiences and enabled some monitoring of quality. Although intended as a community-based programme, in some of the more rural areas, the families were quite dispersed, and some had to travel up to one hour to attend the group sessions. Transport costs were covered by the project.

Data collection

Primary caregivers were interviewed at home at least one month prior to the intervention (baseline) using a structured questionnaire in June 2015. Caregiver data collected included: socio-demographics, quality of life and knowledge in caring for their child. Data on the child included demographics, severity of cerebral palsy, health status, anthropometry and reported

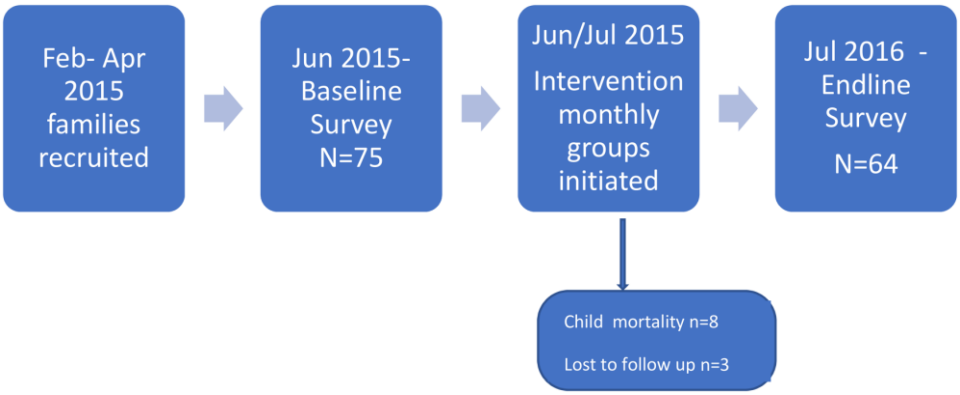


Fig 2. Pre/Post evaluation design pathway.

https://doi.org/10.1371/journal.pone.0202096.g002

feeding difficulties. Data were collected electronically using a tablet (Google Nexus 7) and Open data kit software. The same respondent (primary caregiver) was re-interviewed 13 months later, 1–2 months after completion of the last training session (endline). See Fig 2

Amongst caregivers, the PedsQL™ Family Impact measure [24], was used to quantitatively assess the impact of paediatric conditions on the quality of life of parents and the family. The PedsQL™ measures parents' self-reported physical, emotional, social, and cognitive functioning, communication, and worry, as well as daily activities of the family, and family relationships, and has been validated and tested in different international settings [25–27]. Linguistic validation of the PedsQL tools was conducted in three languages Twi, Gruni, and Kusaal) which included forward and back translations by linguistic experts and further modification following cognitive field testing in the three sites, in line with the translation guidelines [28]. Caregivers were asked about their level of knowledge and confidence in caring for their child with five possible response options from 'none' to 'lots' of knowledge or confidence, and additional questions to assess their experience of treatment and diagnosis.

Severity of cerebral palsy was assessed using the Gross Motor Function Classification System (GMFCS) [29], an internationally-recognised system, which classifies cerebral palsy according to five levels of physical functioning. Data on the child's feeding were collected using structured questions adapted, with input from the author, from a previous study of children with cerebral palsy in Bangladesh [30]. Eight questions were asked about frequency of difficulties with different aspects of eating and drinking, rated on a five-point scale from 'never' to 'always [30]. Reported health of the child was measured with three questions taken from the Ghana DHS survey about whether their child has experienced diarrhoea, fever or cough in the last two weeks [31], and one question about experience of a serious health condition requiring hospital admission in the last 12 months.

Anthropometric measures were taken using standardised protocols for our population. Standing height was recorded to the nearest 0.1cm for children $>$ 5 years. Recumbent lengths were taken for children $<$5 years, where possible, and knee height [32] (CLPR65 Anthropometric Caliper, MediForm, Oregon, USA) was recorded for all children to the nearest 0.1cm. Following WHO best-practice procedures [33], height and length measurements were obtained twice by two independent observers: the average was taken as the final measurement if they agreed to within $<$0.5cm, else both re-measured until agreement was achieved. Mid Upper Arm Circumference (MUAC) was recorded for all children (mm gradation MUAC tape, Teaching

Aids at Low Cost. Weight was recorded to the nearest 0.1kg. Children unable to stand were held by their caregiver, then the caregiver was weighed separately to calculate the child's weight.

Data analysis

Data were analysed using Stata 13 [34]. Total and summary scores from the PedsQL were calculated as the sum of all items divided by the number of items answered. These scores were converted into scores out of 100 with higher scores indicating better quality of life [24]. For the purposes of analysis, the 5 level GMFCS was reclassified into three groups: mild (levels 1 and II), moderate (levels III) and severe (levels IV and V). A composite feeding score comprised of the eight feeding/drinking questions was generated which ranged from 0 (extreme difficulties) to 100 (no difficulties). To assess the internal consistency of this composite scale we calculated Cronbach's alpha coefficients, all which were >0.7 with item-total correlations >0.3 as per recommended guidelines for reliability [35]. Knee height was used as a proxy measure where standing height could not be performed [32]. The line of best fit on a scatter graph of the relationship between recumbent length and knee height was used to predict the heights of those children for whom data were unobtainable. This method was used because of a lack of validated published formula (for converting knee height to height) available for this specific study population. Z scores were calculated based on WHO growth standards using the Emergency Nutrition Assessment and WHO Anthroplus software [36] for weight-for-age (WAZ) (children <10years only), height-for-age (HAZ) and weight-for-height (WHZ) (children ≤5 years only) Children with WAZ/HAZ//WHZ scores between <2 and ≥3 were defined as stunted/wasted/underweight respectively and those with z scores <-3 were defined as severely. For MUAC, wasted was defined as 115mm to 124mm and severe wasting as <115mm. Children with extreme z-score values (greater than >5 or 6/less than -5 or -6, depending on the measure) were excluded from the analysis since they were more likely measurement errors than truly very large or small [37]. The prevalence of stunting, wasting and underweight was calculated, as well as the mean z-scores.

The standard mortality ratio was calculated with data from standard UN child model life tables for children 1–5 years [38] and those from Ghana for children of 1–12 years [39].

Outcomes at baseline and endline were compared using the McNemars tests for binary variables. Continuous variables were compared using the paired t-test (normally distributed data) or Wilcoxon sign rank test (if data were skewed). Analysis were restricted to respondents who were included at both baseline and endline.

Ethics

Ethics approval was obtained from the London School of Hygiene and Tropical Medicine and from the Noguchi Memorial Institute for Medical Research (NMIMR), University of Ghana. Informed written consent was obtained from all participating caregivers, with a signature or thumbprint as appropriate. Children were referred to nutritional services and for assistive devices according to clinical need, and the CBM (international NGO) child protection policy was adhered to.

Results

Training programme

The adherence by facilitators to the training approach was overall assessed to be 'good' by the project coordinator, who visited each group once during the project period. Attendance at the training sessions was high with 92% of caregivers completing all training sessions.

Study population

A total of 75 primary caregiver-child pairs were included at baseline and 64 (84%) and endline. Of those lost to follow up, eight died, and three did not complete the training programme (attended <3 sessions). Socio-demographic characteristics between study participants and those lost to follow-up were similar except girls were more likely to be lost than boys (p = 0.03) (see Table 1).

Table 1 describes the characteristics of the study population. The majority, (72%) of children were under 5 years with a mean age of 3.8 years (SD 2.69). Half of the children had severe cerebral palsy. Caregivers were mainly (98%) female and the majority were mothers (80%) or grandparents (16%); 67% were married, whilst only half of the biological fathers lived in the same house as their child and 43% of the children saw their father less than monthly. 89% described their profession as farming, trading, or a small business such as tailoring. Although, only 42% said they had been able to work in the last month. See Table 1 for details.

Impact of the programme on the caregiver

The average total caregiver QoL score was low (12.5, SD 18.6) at baseline and increased significantly to 51.4 (SD 23.6) at follow up ($p<0.001$). The improvement was significant across all three summary scales (parent, family, and combined) and across eight domains of physical, emotional, social, cognitive, communication functioning, worry, daily relationships and family relationships ($p<0.0001$). We assessed this change among caregivers of children with mild, moderate, and severe cerebral palsy separately and found significant improvements in QoL was evident within each severity group ($p <0.001$)Table 2.

Knowledge and confidence in taking care of child

At baseline, only 13% of caregivers had heard of the condition 'cerebral palsy'. Overall levels of diagnosis of cerebral palsy prior to this study were very poor: 49% of caregivers claimed they had never received a diagnosis, 15% had been told by a health professional it was 'something related to the brain' and 21% reported a diagnosis provided by a traditional healer. At baseline, the vast majority (94%) reported no or low levels of knowledge of their child's condition (Table 3). At endline, there was a significant increase in the proportion reporting good/lots of knowledge: from 6% to 73% ($p<0.001$). In terms of confidence in how to care for their child, at baseline half (49%) of caregivers reported a low level or no confidence. At endline, the proportion who felt they had good or lots of confidence had increased significantly from 36% to 89% ($P<0.001$). See Table 3.

Feeding and drinking

At baseline, at least 45% of caregivers reported problems often/always with the eight different domains of feeding and drinking as shown in Fig 3. At endline, there was a significant reduction in the proportion of parents who reported problems often/always in four domains (child eating and drinking, self-feeding, needs help feeding and caregiver worry about child feeding). Responses to the other domains (choking, eating the same as others, being unhappy during mealtimes, whether the child is eating enough) remained similar between baseline and follow up. In terms of the composite feeding score, there was a significant improvement in the median score from 29.7 (SD 31.4) at baseline to 51.6 (29.8) at endline ($p<0.001$).

Table 1. Study population characteristics.

	n	%
Child variables		
Sex		
Male	38	59
Female	26	41
Child age Group		
18months-2 years	25	39
3–4 years	21	33
5+ years	18	28
Cerebral Palsy severity		
Mild	15	23
Moderate	17	27
Severe	32	50
Caregiver variables		
Age group		
<30	19	30
30–40	29	45
>40	16	25
Sex		
Male	1	2
Female	63	98
Relationship to child		
Mother	51	80
Father	1	2
Grandparent	10	16
Sibling	2	3
Worked in past month (other than domestic)	27	42
Attended school	28	44
Highest level of schooling completed		
None	33	43
Primary	18	24
Secondary	22	29
Tertiary	3	4
Marital status		
Married/living together	43	67
Divorced/separated	6	9
Widowed	5	8
Never married/lived together	10	16
Where does child's biologic father live*		
Not in household	38	51
In household	35	47
Not known	2	3
How often has father seen child in past 6 months		
Daily	37	50
Monthly	3	4
< monthly	11	16
Not seen	20	27
Not known	2	3

(*Continued*)

Table 1. (Continued)

	n	%
Occupation		
Farming	24	32
Trader	20	27
Small business (e.g. dress making, hairdressing)	22	30
Professional	5	7
Other	3	4

*Included fathers who had died (n = 2)

https://doi.org/10.1371/journal.pone.0202096.t001

Child's health and wellbeing

There were significant improvements in caregiver's perception of their child's physical and emotional health. The proportion of caregivers rating their child's health as good, very good, or excellent increased from 34% (baseline) to 73% (endline, $p<0.001$) for physical health and from 36% to 64% for emotional health ($p<0.001$, Table 3). However, most children had experienced a serious health problem (i.e. a problem the caregiver felt required treatment) in the last 12 months at both baseline (70%) and endline (67%). Illness in the last two weeks was common with 64% of the population at baseline reporting illness in the past two weeks (at least one of: fever (38%), Cough/breathing difficulties (39%) diarrhoea (13%)). At endline, this was lower with 50% ($p = 0.05$) of caregivers reporting illness in the past two weeks: (fever: 25%, Cough/breathing difficulties: 25%; diarrhoea: 18%). See Table 3.

Nutrition

As shown in Table 3, the prevalence of malnutrition was high at both time points. At baseline, 63% of children were classified as underweight and this remained similar at endline ($p = 0.5$). The proportion of children classified as stunted was 53.8% at baseline and 64.1% at endline

Table 2. Baseline and endline caregiver QoL scores and mean change between the two-time points.

	Baseline Median score IQR)	Endline Median score (IQR)	P-value*	Mean change (95% CI)
Summary scores				
Total	12.5 (21.5)	51.4 (23.6)	P<0.001	+31.3 (25.6–37.0)
Parent	13.8 (21.3)	47.5 (25.6)	P<0.001	+28.9 (22.9–34.9)
Family	14.1 (46.9)	57.8 (30.0)	P<0.001	+31.9 (23.5–40.3)
Sub-scale scores				
Physical functioning	6.7 (27.1)	50.0 (50.0)	P<0.001	+26.7 (19.2–34.3)
Emotional functioning	10.0 (22.5)	47.5 (42.5)	P<0.001	+33.4 (26.1–40.8)
Social functioning	6.3 (28.1)	37.5 (56.3)	P<0.001	+25.9 (17.8–34.1)
Cognitive functioning	10.0 (35.0)	50.0 (40.0)	P<0.001	+29.2 (21.8–36.6)
Communication functioning	8.3 (16.7)	66.6 (37.5)	P<0.001	+45.4 (37.5–53.4)
Worry	10.0 (20.0)	50.0 (35.0)	P<0.001	+31.7 (24.4–39.1)
Daily activities	0 (16.7)	50 (45.8)	P<0.001	+32.3 (23.2–41.4)
Family relationships	5.0 (50.0)	62.5 (31.6)	P<0.001	+31.6 (21.1–42.2)

*Wilcoxon Sign Rank test comparing baseline and endline scores; NB: Baseline and endline data were skewed and therefore median scores and a non-parametric statistical test were used. Change scores were normally distributed and therefore mean values were derived. IQR = Interquartile Range

https://doi.org/10.1371/journal.pone.0202096.t002

Table 3. Caregiver knowledge and confidence and child's health and wellbeing at baseline and endline.

	Baseline N (%)	Endline N (%)	P* value
Caregiver knowledge in caring for child			
None/low knowledge	60 (94%)	17 (27%)	<0.001
Good or lots of knowledge	4 (6%)	47 (73%)	
Caregiver confidence in caring for child			
None/low confidence	41(64%)	8 (13%)	<0.001
Good or lots of confidence	23 (36%)	89%)	
Caregiver's perception of child's physical health			
Poor/fair	42 (66%)	17 (27%)	<0.001
Good/very good/excellent	22 (34%)	47 (73%)	
Caregiver's perception of child's emotional health			
Poor/fair	41 (64%)	23 (36%)	<0.001
Good/very good/excellent	23 (35%)	41 (64%)	
Child had serious health problem in past year	45 (70%)	43 (67%)	0.63
Child had illness in past 2 weeks:			
Diarrhoea	8 (13%)	12 (18%)	0.31
Fever	24 (38%)	16 (25%)	0.13
Cough / Difficulty breathing	25 (39%)	16 (25%)	0.06
Any of above 3 illnesses	41 (64%)	32 (50%)	0.05

*P-value from McNemars test comparing baseline and endline

https://doi.org/10.1371/journal.pone.0202096.t003

(p = 0.06). Wasting was evident in 60% of children (< 4 years only) at baseline with 45.2% at endline (p = 0.01). Using MUAC, 15.2% were classified as wasted at baseline and 21.7% at endline.

We compared the proportion of children who were underweight at baseline and endline for children with mild, moderate, and severe CP separately and found the trends within each severity level were similar to that for the full population combined. See Table 4.

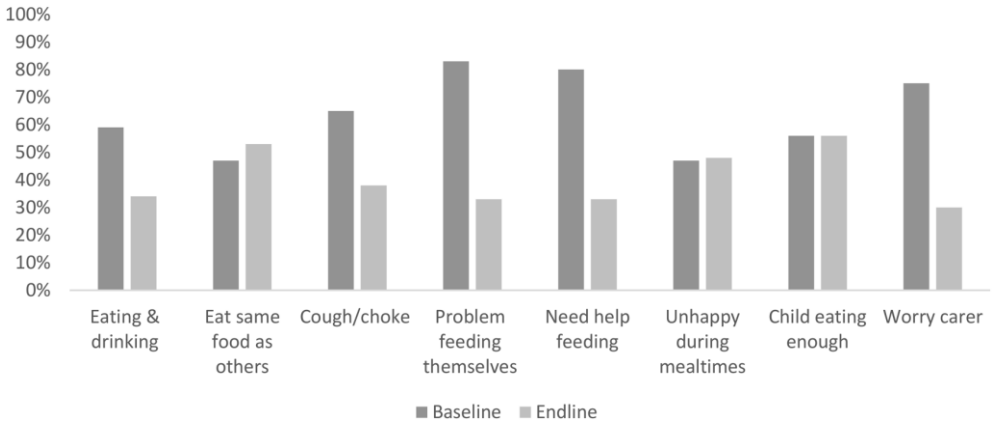


Fig 3. Proportion of caregivers reporting problems always/often with different aspects of child's feeding at baseline and endline.

https://doi.org/10.1371/journal.pone.0202096.g003

Table 4. Prevalence of malnutrition among children at baseline and endline.

	All ages**				Children < 5years (at baseline)			
	Baseline		Endline		Baseline		Endline	
	N	% (95% CI)	N	% (95% CI)	N	% (95% CI)	N	% (95% CI)
Weight for Age								
'Normal'	21	36.8 *(25.1–50.3)	20	34.5 (23.1–48.8)	15	34.9 (21.7–50.7)	15	34.1 (21.3–49.7)
Underweight	14	24.5 (14.8–37.7)	10	17.2 (10.4–29.6)	12	27.9 (16.2–43.6)	9	20.5 (10.7–35.5)
Severely underweight	22	38.5 (28.5–52.6)	28	48.2 (35.4–61.3)	16	37.2 (23.7–53.0)	20	45.5 (31.0–60.7)
Mean z-score (95% CI)		-2.6 (-2.9- -2.2)		-2.8 (-3.1- -2.3)		-2.6 (-2.9- -2.1)		-2.7 (-3.2- -2.3)
p-value*				P = 0.08				P = 0.06
Height for Age								
'Normal'	29	46.0 (33.9–58.6)	23	35.9 (24.9–48.7)	24	52.2 (37.4–66.6)	18	39.1 (25.8–54.3)
Stunted	17	26.9 (17.3–39.5)	16	25.0 (15.7–37.4)	10	21.7 (11.8–36.5)	12	26.1 (15.1–41.1)
Severely stunted	17	26.9 (17.3–39.5)	25	39.1 (27.7–51.8)	12	26.1 (15.1–41.1)	16	34.8 (22.1–50.0)
Mean z-score (95% CI)		-2.3 (-2.6- -1.9)		-2.7 (-3.0- -2.4)		-2.2 (-2.6- -1.8)		-2.6 (-3.0- -2.2)
p-value*				P = 0.003				P = 0.002
Weight for height								
'Normal'					12	40.0 (23.4–59.1)	17	54.8 (36.5–71.9)
Wasted					12	40.0 (23.4–59.1)	4	12.9 (4.6–31.6)
Severely wasted					16	20.0 (8.8–39.2)	10	32.3 (17.7–51.4)
Mean z-score (95% CI)						-2.1 (-2.5- -1.6)		-1.9 (-2.5- -1.3)
p-value (z scores)*								P = 0.24
Mid Upper Arm Circumference								
'Normal' (> = 125mm)					43	84.7 (70.7–92.7))	36	78.3 (63.5–88.1)
Wasted (115-124mm)					10	15.2 (7.2–29.2)	6	13.0 (0.6–26.8)
Severely wasted (<115mm)					0	0	4	8.7 (3.1–21.7)
Mean MUAC (95% CI)						144.8 (139.3–150.4)		144.4 (137.9–150.8)
p-value (mean MUAC)*								P = 0.8

*P value comparing z scores at baseline and endline.

** Weight for age calculated for children <10 years as per guidelines.

https://doi.org/10.1371/journal.pone.0202096.t004

Child mortality

In total, eight children died over the 12-month study period; mainly in the early part of the programme, all with severe cerebral palsy, and classified as malnourished at baseline and referred to nutrition services. A confirmed diagnosis for death was not provided by caregivers except in one case where sepsis and acute malnutrition was diagnosed. The standard mortality ratio for children 1–5 years, showed that the study children were 14.61 times more likely to die than children in the standard population for developing countries ($P < 0.05$). For the wider age range of children (1–12 years) the standard mortality ratio was 5.88 ($P < 0.05$), meaning that with cerebral palsy of this age were 5.88 times likely to die than children in the standard Ghana population.

Discussion

This study in Ghana found significant improvements in QoL among caregivers of children with cerebral palsy who participated in a parent training programme offered through the establishment of a support group in a nearby community. Significant improvements were also found in caregiver reported knowledge and confidence in caring for their child, and in some

aspects of child feeding. Reported serious health conditions and levels of malnutrition in these children were high both before and after the intervention.

The initial low caregiver QoL scores reported at baseline in this study aligns with a previous study in Bangladesh using the same tool [27] and other studies in LMIC which have found high levels of anxiety, depression, stress and poorer quality of life among caregivers of children with disabilities [12, 14, 27, 40–42]. The few studies which have included caregiver outcomes for home and community-based interventions, have generally focussed on one or two measures of improvements in maternal knowledge and stress, and parent satisfaction with services [43] [20] [44–46]. In our study, the reported improvement in knowledge and confidence in caring for their child is encouraging; and arguably, more importantly, the emphasis on problem solving and caregiver empowerment, within a support group setting, has the potential to offer a more sustainable mechanism for improving long term outcomes for the child and family. There is a clear need for such an approach which also supports task-sharing for rehabilitation, given the limited number of therapist and rehabilitation services in the Ghana context. However, this intervention does not aim to replace specialist services, rather for referrals to be strengthened, and for empowered caregivers to be able to demand these services, within a rights-based framework. Follow- up research with the support groups is now required to understand how these groups have been developed and sustained.

Evidence of improvements in child outcomes was more mixed. Some aspects of mealtimes and feeding their child were improved. Other studies have similarly highlighted the particular challenges of feeding for children with disabilities, including children with cerebral palsy [30, 47–50], and our baseline study showed feeding difficulties were also strongly associated with poorer caregiver QoL and child malnutrition [51]. Yet few studies have evaluated interventions aimed at improving nutritional outcomes for these children in low resource settings: we only found one study in Bangladesh study demonstrated improvements in nutritional outcomes through parental support and training, exclusively focussed on a feeding intervention [30].

Despite some positive changes in reported feeding experiences by the caregiver, levels of malnutrition remained high with some two-thirds of the population malnourished at both baseline and endline. This high level of malnutrition is mirrored in a study in Uganda [50] and is considerably higher than 2014 DHS estimates for the general population in Ghana where 11% of children under 5 years were underweight, 5% wasted and 19% stunted [31]. To some extent this reflects a vulnerable group whose growth potential—even in ideal environments—is below that of non-disabled children [52, 53]. However, unreached potential for growth clearly deserves further future attention. Whilst the training programme covers a range of topics, it is possible that: more emphasis on feeding and drinking practices would have improved anthropometry; more specific guidance on nutrient-dense feeds is required; further strengthening referrals pathways to nutrition programmes is needed. In addition, more attention should be given to the specific needs of younger children as they are weaned and transition to solids. There are also other documented complex challenges for inclusive child nutrition programmes including: the role that stigma and discrimination and poverty can play, the lack of inclusive nutritional services, and a need for stronger linkages in programming between nutrition and disability, poverty, and human rights [54].

The high mortality ratio highlights the extreme vulnerability of children of all ages, particularly for children aged 1–5 years who were almost 15 times likely to die than general child population of the same age. We were unable to identify other data on SMR among children with CP in LMIC. However, high rates of mortality have been noted in Bangladesh where 18% of 92 children with cerebral palsy died over a 3-year period; the most severely malnourished and severely disabled were most likely to die [55]. These findings underline the need to prioritise

early intervention to prevent and manage serious malnourishment, and to establish closer linkages between disability and malnutrition.

In this study the child's emotional and physical health was reported as improved by the caregiver but reported difficulties with breathing (25%) and diarrhoea (18%) were still very high in comparison with the national Ghana DHSS survey data of 12% of children that experience diarrhoea, and 4% with ARI, at 2 weeks previous to the survey [31]. Our findings are aligned with the small number of studies which demonstrate children with disabilities are more likely to experience poorer health [2, 6, 56, 57].

The absence of fathers in households of children with cerebral palsy highlighted in this study deserves attention. Overall there is little data from LMICs exploring this issue, despite the multi-fold implications, including impact on household income, on caregiving roles, the implications for any community and home -based intervention programme, and to ensure that any intervention does not further burden the gendered nature of caregiving. A detailed analysis of the intersectionality of gender and disability and caregiving is likely to be important to further strengthen this intervention.

Finally, the results show that a relatively simple intervention can improve outcomes for caregivers of children. There needs to be aspects of the training and approach which need strengthening, and this is underway. The model of establishing a support group, emphasising caregiver empowerment, potentially offers a more sustainable mechanism to address needs for a child with a disability who requires care over a lifetime. A longer-term re-assessment of caregivers and their children is recommended, also to better understand the sustainability of these support groups.

Study strengths and limitations

Ours is one of very few studies evaluating the impact of a community based, family focussed intervention for children with cerebral palsy in low income settings. It was conducted across eight different sites in Ghana, using standardised questionnaires, and clinical assessment of all participating children.

The participant numbers were not large, they were comparable to other studies conducted with children with cerebral palsy [20, 43, 44]. The target families were identified in areas supported by the Presbyterian Church of Ghana, who typically work in areas of greater deprivation, and so there may have been a selection bias, with our sample more likely to be poorer than the general population. This may limit the generalisability of the findings and might also mean that impact was more limited by poverty.

We did not include a control group of caregivers and children who did not receive the intervention against which to compare, because of ethical reasons. We cannot rule out the role of social desirability in the responses of caregivers in their rating of QoL, caring and ratings of child health. We did not assess children's quality of life, due to the lack of suitable tools for younger children, without using parents to offer a proxy measure. This should be explored in future studies. Future studies should also explore longer term impact of the training and sustainability of the support groups.

Conclusion

There is a need for effective home and community-based programmes for children with disabilities, and their families. This study showed promising outcomes for improving the lives of the primary caregiver, following a relatively simple participatory training programme delivered through local support groups. With a focus on caregiver empowerment within a rights-based approach, the benefits are potentially more sustainable, with the right kind of ongoing

support, and transformative for families. The results for the children were mixed and highlight an urgent need for more attention to be paid to nutrition and feeding, which are underway.

Acknowledgments

We would like to thank additional advisory board members including, Dr Norgrove Penny, Dr Eben Badoe, Jedidia Abanga, Dr Sarah Bernays, Dr Mel Adams, Dr Marko Kerac, and Maxwell Akandem. Most importantly, we would like to thank all the participating families, especially the caregivers and children who participated in the programme, and gave their valuable time for the researchers.

Author Contributions

Conceptualization: Maria Zuurmond.

Data curation: Maria Zuurmond.

Formal analysis: Sarah Polack.

Funding acquisition: Maria Zuurmond.

Investigation: Maria Zuurmond, David O'Banion, Sandra Carsamar.

Methodology: Maria Zuurmond, David O'Banion, Melissa Gladstone, Gifty Gyamah Nyante.

Project administration: Maria Zuurmond, Sandra Carsamar, Marjolein Baltussen, Gifty Gyamah Nyante.

Software: Sarah Polack.

Supervision: Maria Zuurmond, Sarah Polack.

Writing – original draft: Maria Zuurmond, Sarah Polack.

Writing – review & editing: Maria Zuurmond, Melissa Gladstone, Marko Kerac, Marjolein Baltussen, Cally J. Tann, Sarah Polack.

References

1. UNICEF. State of the World's Children: children with disabilities New York: UNICEF, 2013.
2. World Health Organization, World Bank. World report on disability Geneva: WHO, 2011.
3. Donald KA, Kakooza AM, Wammanda RD, Mallewa M, Samia P, Babakir H, et al. Pediatric Cerebral Palsy in Africa Where Are We? Journal of child neurology. July 2015; 30(8):963–71. https://doi.org/10.1177/0883073814549245 PMID: 25296926
4. Colver A, Fairhurst C, Pharoah PO. Cerebral palsy. Obstetrical & Gynecological Survey. 2014; 69(8):447–9.
5. Gladstone M. A review of the incidence and prevalence, types and aetiology of childhood cerebral palsy in resource-poor settings. Annals of Tropical Paediatrics. 2010; 30(3):181–96. https://doi.org/10.1179/146532810X12786388978481 PMID: 20828451.
6. Kuper H, Monteath-van Dok A, Wing K, Danquah L, Evans J, Zuurmond M, et al. The Impact of Disability on the Lives of Children; Cross-Sectional Data Including 8,900 Children with Disabilities and 898,834 Children without Disabilities across 30 Countries. PloS one. 2014; 9(9):e107300. https://doi.org/10.1371/journal.pone.0107300 PMID: 25202999
7. Bedford J, Mackey S, Parvin A, Muhit M, Murthy G. Reasons for non-uptake of referral: children with disabilities identified through the Key Informant Method in Bangladesh. Disability & Rehabilitation. 2013; (0):1–7.
8. Nesbitt R, Mackey S, Kuper H, Muhit M, Murthy G. Predictors of referral uptake in children with disabilities in Bangladesh-Exploring barriers as a first step to improving referral provision. Disability and rehabilitation. 2012; 34(13):1089–95. https://doi.org/10.3109/09638288.2011.634943 PMID: 22136387

9. United Nations. The UN convention on the rights of persons with disabilities 2013 [cited 2017 4th September]. https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html.
10. United Nations. Sustainable Development Goals 2015 [cited 2017 26/09]. https://sustainabledevelopment.un.org/.
11. World Health Organization. Global Strategy for Women's, Children's and Adolescents' Health, 2016–2030 2016 [cited 2017 26/09]. http://www.who.int/life-course/partners/global-strategy/global-strategy-2016-2030/en/.
12. Gona JK, Mung'ala-Odera V, Newton CR, Hartley S. Caring for children with disabilities in Kilifi, Kenya: what is the carer's experience? Child Care Health Dev. 2011; 37(2):175–83. Epub 2010/07/22. https://doi.org/10.1111/j.1365-2214.2010.01124.x PMID: 20645990
13. Hartley S, Ojwang VP, Bagawemu A, Ddamulira M, Chavuta A. How do carers of disabled children cope? The Uganda perspective. Child: Care, Health and Development. 31 2 167–180. 2005.
14. Mobarak R, Khan NZ, Munir S, Zaman SS, McConachie H. Predictors of stress in mothers of children with cerebral palsy in Bangladesh. J Pediatr Psychol. 2000; 25(6):427–33. Epub 2000/09/09. PMID: 10980047.
15. Nakamanya S, Siu GE, Lassman R, Seeley J, Tann CJ. Maternal experiences of caring for an infant with neurological impairment after neonatal encephalopathy in Uganda: a qualitative study. Disability & Rehabilitation. 2014;(0):1–7.
16. Tinney M, Chiodo A, Haig A, Wiredu E. Medical rehabilitation in Ghana. Disability and rehabilitation. 2007; 29(11–12):921–7. https://doi.org/10.1080/09638280701240482 PMID: 17577726
17. World Confederation of Physical Therapy (2017) Ghana Physiotherapy Association http://www.wcpt.org/node/24012 [Accessed 14/03/2018].
18. Rosenbaum P. Family and quality of life: key elements in intervention in children with cerebral palsy. Developmental Medicine & Child Neurology. 2011; 53(s4):68–70.
19. Donald KA, Samia P, Kakooza-Mwesige A, Bearden D. Pediatric Cerebral Palsy in Africa: A Systematic Review. Seminars in pediatric neurology. 2014; 21(1):30–5. https://doi.org/10.1016/j.spen.2014.01.001 PMID: 24655402
20. Yousafzai AK, Lynch P, Gladstone M. Moving beyond prevalence studies: screening and interventions for children with disabilities in low-income and middle-income countries. Archives of disease in childhood. 2014:archdischild-2012-302066.
21. Donald KA, Kakooza AM, Wammanda RD, Mallewa M, Samia P, Babakir H, et al. Pediatric Cerebral Palsy in Africa Where Are We? Journal of Child Neurology. 2014;(Online First Version):http://jcn.sagepub.com/content/early/2014/10/01/0883073814549245.
22. LSHTM, Hambisela. Getting to know Cerebral Palsy: working with parent groups- a training resource for facilitators, parents, caregivers and persons with cerebral palsy London2013 [cited 2016 23/09/]. http://disabilitycentre.lshtm.ac.uk/2013/08/01/publication-of-getting-to-know-cerebral-palsy-manual/.
23. Cerebral Palsy Association. Hambisela: Towards Excellence in Cerebral Palsy. A Training resource for facilitators, parents, caregivers and persons with cerebral palsy Port Elizabeth: Cerebral Palsy Association; 2008. www.hambisela.co.za
24. Varni JW, Sherman SA, Burwinkle TM, Dickinson PE, Dixon P. The PedsQL™ family impact module: preliminary reliability and validity. Health and quality of life outcomes. 2004; 2(1):55.
25. Ab Rahman A, Mohamad N, Imran MK, Ibrahim WPW, Othman A, Aziz AA, et al. A preliminary study on the reliability of the Malay version of PedsQL™ Family Impact Module among caregivers of children with disabilities in Kelantan, Malaysia. The Malaysian journal of medical sciences: MJMS. 2011; 18(4):63. PMID: 22589674
26. Scarpelli AC, Paiva SM, Pordeus IA, Varni JW, Viegas CM, Allison PJ. The Pediatric Quality of Life Inventory™(PedsQL™) family impact module: reliability and validity of the Brazilian version. Health and Quality of Life Outcomes. 2008; 6(1):35.
27. Zuurmond MA, Mahmud I, Polack S, Evans J. Understanding the Lives of Caregivers of Children with Cerebral Palsy in rural Bangladesh: Use of Mixed Methods. Disability, CBR & Inclusive Development. 2015; 26(2):5–21.
28. Mapi Research Institute. PedsQL translations [cited 2016 13/03/2018]. http://www.pedsql.org/translations.html.
29. Wood E, Rosenbaum P. The gross motor function classification system for cerebral palsy: a study of reliability and stability over time. Developmental Medicine & Child Neurology. 2000; 42(05):292–6.
30. Adams M, Khan N, Begum S, Wirz S, Hesketh T, Pring T. Feeding difficulties in children with cerebral palsy: low cost caregiver training in Dhaka, Bangladesh. Child: care, health and development. 2011; 38(6):878–88.

9. United Nations. The UN convention on the rights of persons with disabilities 2013 [cited 2017 4th September]. https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html.
10. United Nations. Sustainable Development Goals 2015 [cited 2017 26/09]. https://sustainabledevelopment.un.org/.
11. World Health Organization. Global Strategy for Women's, Children's and Adolescents' Health, 2016–2030 2016 [cited 2017 26/09]. http://www.who.int/life-course/partners/global-strategy/global-strategy-2016-2030/en/.
12. Gona JK, Mung'ala-Odera V, Newton CR, Hartley S. Caring for children with disabilities in Kilifi, Kenya: what is the carer's experience? Child Care Health Dev. 2011; 37(2):175–83. Epub 2010/07/22. https://doi.org/10.1111/j.1365-2214.2010.01124.x PMID: 20645990
13. Hartley S, Ojwang VP, Bagawemu A, Ddamulira M, Chavuta A. How do carers of disabled children cope? The Uganda perspective. Child: Care, Health and Development. 31 2 167–180. 2005.
14. Mobarak R, Khan NZ, Munir S, Zaman SS, McConachie H. Predictors of stress in mothers of children with cerebral palsy in Bangladesh. J Pediatr Psychol. 2000; 25(6):427–33. Epub 2000/09/09. PMID: 10980047.
15. Nakamanya S, Siu GE, Lassman R, Seeley J, Tann CJ. Maternal experiences of caring for an infant with neurological impairment after neonatal encephalopathy in Uganda: a qualitative study. Disability & Rehabilitation. 2014;(0):1–7.
16. Tinney M, Chiodo A, Haig A, Wiredu E. Medical rehabilitation in Ghana. Disability and rehabilitation. 2007; 29(11–12):921–7. https://doi.org/10.1080/09638280701240482 PMID: 17577726
17. World Confederation of Physical Therapy (2017) Ghana Physiotherapy Association http://www.wcpt.org/node/24012 [Accessed 14/03/2018].
18. Rosenbaum P. Family and quality of life: key elements in intervention in children with cerebral palsy. Developmental Medicine & Child Neurology. 2011; 53(s4):68–70.
19. Donald KA, Samia P, Kakooza-Mwesige A, Bearden D. Pediatric Cerebral Palsy in Africa: A Systematic Review. Seminars in pediatric neurology. 2014; 21(1):30–5. https://doi.org/10.1016/j.spen.2014.01.001 PMID: 24655402
20. Yousafzai AK, Lynch P, Gladstone M. Moving beyond prevalence studies: screening and interventions for children with disabilities in low-income and middle-income countries. Archives of disease in childhood. 2014:archdischild-2012-302066.
21. Donald KA, Kakooza AM, Wammanda RD, Mallewa M, Samia P, Babakir H, et al. Pediatric Cerebral Palsy in Africa Where Are We? Journal of Child Neurology. 2014;(Online First Version):http://jcn.sagepub.com/content/early/2014/10/01/0883073814549245.
22. LSHTM, Hambisela. Getting to know Cerebral Palsy: working with parent groups- a training resource for facilitators, parents, caregivers and persons with cerebral palsy London2013 [cited 2016 23/09/]. http://disabilitycentre.lshtm.ac.uk/2013/08/01/publication-of-getting-to-know-cerebral-palsy-manual/.
23. Cerebral Palsy Association. Hambisela: Towards Excellence in Cerebral Palsy. A Training resource for facilitators, parents, caregivers and persons with cerebral palsy Port Elizabeth: Cerebral Palsy Association; 2008. www.hambisela.co.za
24. Varni JW, Sherman SA, Burwinkle TM, Dickinson PE, Dixon P. The PedsQL™ family impact module: preliminary reliability and validity. Health and quality of life outcomes. 2004; 2(1):55.
25. Ab Rahman A, Mohamad N, Imran MK, Ibrahim WPW, Othman A, Aziz AA, et al. A preliminary study on the reliability of the Malay version of PedsQL™ Family Impact Module among caregivers of children with disabilities in Kelantan, Malaysia. The Malaysian journal of medical sciences: MJMS. 2011; 18(4):63. PMID: 22589674
26. Scarpelli AC, Paiva SM, Pordeus IA, Varni JW, Viegas CM, Allison PJ. The Pediatric Quality of Life Inventory™(PedsQL™) family impact module: reliability and validity of the Brazilian version. Health and Quality of Life Outcomes. 2008; 6(1):35.
27. Zuurmond MA, Mahmud I, Polack S, Evans J. Understanding the Lives of Caregivers of Children with Cerebral Palsy in rural Bangladesh: Use of Mixed Methods. Disability, CBR & Inclusive Development. 2015; 26(2):5–21.
28. Mapi Research Institute. PedsQL translations [cited 2016 13/03/2018]. http://www.pedsql.org/translations.html.
29. Wood E, Rosenbaum P. The gross motor function classification system for cerebral palsy: a study of reliability and stability over time. Developmental Medicine & Child Neurology. 2000; 42(05):292–6.
30. Adams M, Khan N, Begum S, Wirz S, Hesketh T, Pring T. Feeding difficulties in children with cerebral palsy: low cost caregiver training in Dhaka, Bangladesh. Child: care, health and development. 2011; 38(6):878–88.

53. Krick J, Murphy-Miller P, Zeger S, WEIGHT E. Pattern of growth in children with cerebral palsy. Journal of the American Dietetic Association. 1996; 96(7):680–5. PMID: 8675911

54. Groce NE, Kerac M, Farkas A, Schultink W, Bieler RB. Inclusive nutrition for children and adults with disabilities. The Lancet Global Health. 2013.

55. Khan NZ, Ferdous S, Munir S, Huq S, McConachie H. Mortality of urban and rural young children with cerebral palsy in Bangladesh. Developmental medicine & child neurology. 1998; 40(11):749–53.

56. Gottlieb CA, Maenner MJ, Cappa C, Durkin MS. Child disability screening, nutrition, and early learning in 18 countries with low and middle incomes: data from the third round of UNICEF's Multiple Indicator Cluster Survey (2005–06). The Lancet. 2009; 374(9704):1831–9.

57. Kerac M. Improving the treatment of severe acute malnutrition in childhood: a randomized controlled trial of synbiotic-enhanced therapeutic food with long term follow-up of post-treatment mortality and morbidity: University College London; 2011.

Chapter Six: Learning from the Ladder of Life Tool

Photo 5 Photo of group facilitator collecting consent for the study at baseline

In this chapter, I present findings from data collected from using a QoL tool with caregivers, called the 'Ladder of Life' (LoL-QoL). I reflect on what it adds to our understanding of caregiver assessment of the quality of their lives. The findings from this work contribute to Research Objective 1, '*To assess impact of a caregiver training programme upon the lives of children with cerebral palsy and their caregivers in Ghana'*. The statistical tests (using Stata) were conducted by SP, whilst I conducted the basic statistical analysis (Microsoft Excel) and coding.

"It can't get worse."

Background

Concepts of QoL

The concepts of 'quality of life' and 'wellbeing' are often used interchangeably (Camfield et al., 2009b, Camfield and Skevington, 2008). A brief overview of theories to explain these concepts are detailed in the introductory section of **Chapter seven**. In summary, early theories on QoL and wellbeing focused on individual achievement of happiness and satisfaction (Bowling, 2014, Andrews and Withey, 1976, Bowling, 1999); or on an individual's capability to pursue their goals (Sen, 1993, Deneulin and McGregor, 2010). The importance of social relationships and understanding of the collective character of human wellbeing, as well as of the individual, came later (Deneulin and McGregor, 2010, Ruta et al., 2007). The World Health Organization definition of QoL recognises both the subjective and multi-dimensional nature of quality of life in their definition, and it is this definition drawn upon in this thesis:

> 'An individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs, and their relationship to salient features of their environment.' (WHOQOL group, 1995P.1405).

Measuring QoL

Given the recognised complexity and multi-dimensional nature of QoL, as well as the lack of consensus around the conceptualisations of QoL, it is therefore perhaps not unsurprising that there are a vast array of instruments available to assess QoL. These include tools which focus on health-related QoL for specific health- or disease-related issues, and which are designed to be sensitive to changes in relation to that particular condition (Gill, 1995). These can be uni-dimensional, focusing on one aspect of functioning linked to a condition, or they can be multidimensional and bring in broader psychological and social aspects of life. In contrast generic health-related QoL measures are not condition or disease-specific. Broader still, generic QoL measures are not health-specific and aim to capture a more global life satisfaction measure of how a person feels about their life. The advantage of these more generic measures is that they can be applied to populations with a range of conditions, and they recognise that other key areas of life such as the environment, finances and education are also considered in a broader QoL concept (Bowling, 1999, Bowling, 2014).

The different types of instruments for measuring self-reported QoL can include a single question or a global score, such as 'overall how do you rate your health?', where although the concept of QoL is multi-dimensional, it is the respondent that interprets this for themselves. This has the advantage of being simple and easy to use, and also captures the participant's own perception of what they consider to be important in their lives. However, arguably they have several limitations, notably that they are vague and hard to interpret, and may be less reliable compared to using multiple questions (Gill, 1995). In contrast, multi-item scales/sub-scales include several questions designed to measure one particular

concept, usually with the same response options, and total/sub-scale scores are generated by averaging the responses. The argument made is that the use of multiple questions can more reliably capture specific concepts under study and may be less prone to measurement error (Fayers and Machin, 2013). A third type of instrument used is a battery of several single items that are reported separately.

The methods of recording responses also vary across instruments, including simple binary responses such as 'yes/no', use of Likert scales and visual analogue scales, where respondents are asked to rate their state along a scale (e.g. between 1 and 10). Importantly, to be useful, scales should show good validity (measures what it is intended to measure), reliability (produces consistent and reproducible results), and be responsive (able to detect change) .

The *PedsQL™* measure, detailed in the previous **Chapter five**, is a health-related QoL measure, developed specifically for caregivers of children with chronic health conditions. It assesses parents' self-reported physical, emotional, social, and cognitive functioning, communication, and worry, as well as daily activities of the family, and family relationships. It is relatively widely used in different contexts and has been validated and tested in different international settings (Ab Rahman et al., 2011, Scarpelli et al., 2008). It is a multi-scale instrument, using multiple questions and summary scores within each domain. (Fayers and Machin, 2013).

In comparison to the *PedsQL™*, the LoL-QoL measure is an example of a generic QoL measure. It uses a visual analogue scale (VAS) where the participant is asked to rate the

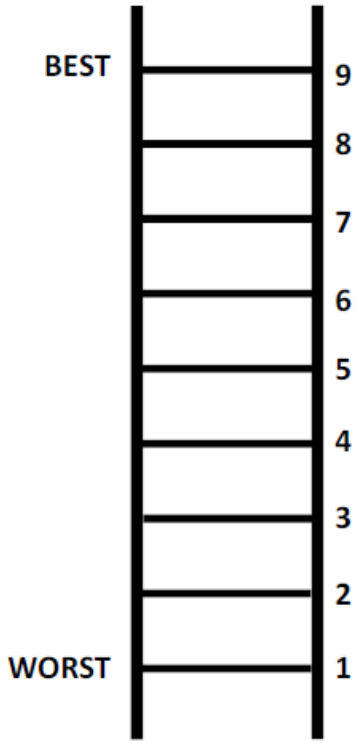
overall quality of their lives on a ladder scale from 1-9 (details further described in the next section). Further, the LoL also combines the VAS with open questions designed to offer explanatory factors that shape their subjective score. The LoL-QoL tool used in the study is based on the version used in the Young Lives longitudinal study on childhood poverty (Camfield and Tafere, 2009), which in turn, is an adaptation of the Cantril ladder (Cantril, 1965). Criteria for the selection of this tool for piloting in this study included the following factors: 1) a simple measure which provided one simple overall score, 2) a tool which was easy to administer to caregivers, especially where literacy and education levels are low, 3) a tool which offers additional explanatory qualitative information to substantiate the score and thus help elucidate underlying factors influencing the caregiver QoL.

Whilst the use of the original Cantril Ladder has been very widely used for international comparisons of life satisfaction (Helliwell and Barrington-Leigh, 2010), the modified version (LoL-QoL) used by the Young Lives study has been less widely applied in different international settings (Camfield and Tafere, 2009). This version adds a narrative component to the tool, to capture perspectives on what will help positively change their QoL, which is further detailed below. I wanted to test it in the Ghana setting, specifically in a setting where there are often low levels of education and literacy. Throughout this chapter and thesis, I use the word 'tool' to describe both the score given on the ladder scale, and the ensuing discussion and explanatory qualitative reasons provided with the score.

The purpose of testing the tool was two-fold; to explore how it functioned in terms of feasibility and relevance in the Ghana setting, and to see if it provided additional useful information to the *PedsQL™*.

In this chapter I briefly examine the acceptability of the tool (including the metaphor of a 'ladder') in the Ghana context, and present on the findings. A full assessment of the psychometric properties (validity and reliability) of the tool was beyond the scope of this thesis and study. Further, analysis of the psychometric properties such as construct validity (e.g. comparing the LoL-QoL to the *PedsQL™*) was not possible due to the relatively small sample size and heavily skewed response distribution towards poor QoL. This skewed response likely reflects the relative lack of heterogeneity in the sample; they were all female caregivers of children with moderate to severe cerebral palsy from rural areas of Ghana. However, in-depth assessment of validity and reliability of this tool with a larger and more heterogeneous sample (e.g. including caregivers of children with less severe cerebral palsy) is a recommendation for future research.

Description of tool



The tool consists of a ladder with nine steps (see Figure 7). The version from the Young Lives study was used (Camfield and Tafere, 2009), which asks participants to rate their QoL using the ladder with the explanation that '*the ninth step, at the very top, represents the best possible life for the caregiver and the bottom represents the worst possible life.'* The data collector emphasises that the ladder refers to all aspects of his/her life (economic, health, social, personal, etc.).

Figure 7 Image of ladder of life

The participant is then asked to state 1) '*what would help move them up the ladder?*' and asked to give the main factor(s) which could contribute to this. This question is assumed to reflect their sense of optimism and feelings of control over the future (Camfield and Tafere, 2009). In this study we also asked an additional question: '*What would cause you to move down the ladder?',* as the expectation was that this would also provide useful data. The instrument is available in Appendix 8: Baseline survey questionnaire.

Methods

Setting and Sample

In summary, the tool was first pilot-tested as part of the overall testing of the full survey detailed in **Chapter four**. The baseline survey was conducted with the 75 caregivers of children with cerebral palsy from across all eight regions of Ghana. Data from this measure were collected from 71 caregivers. At endline, data were

obtained from 64 caregivers. Eight respondents were not followed up at endline because the child had died and/or loss to follow up.

The children were aged 18 months to 12 years, with varying levels of cerebral palsy. Further details of the sample and setting has already been detailed in **Chapter four** of this thesis, and also in the published paper on impact in **Chapter five**.

Data collection

The LoL-QoL measure was administered to all caregivers as part of the quantitative survey after the *PedsQL™*. The questions were asked towards the end of the survey, after some rapport had been built with the caregivers. The diagram of a ladder with nine steps was printed onto a piece of card and shown to the caregivers, and they were asked to say, or point to, where they felt they were on the ladder. Qualitative information on the reasons to 'move up' (i.e., improve their QoL) or 'down the ladder' (i.e. worsen their QoL) was captured in a short sentence or phrase by the data collector. There was no limit given on the number of reasons that could be given, but the guidance was for 1-2 key reasons to be captured by the data collector.

The QoL-LoL was administered to all caregivers at baseline (n=71) and endline (n=64). However, the number of caregivers asked to provide statements to explain what would improve or worsen their lives varied depending on their reported 'score': if caregivers reported a score of '1' as '*worst possible life'*, they were not then asked what factors would make them move down the ladder and make their lives worse. Similarly, if caregivers self-reported a score of '9', the '*best possible life*', they were not then asked what would

improve their lives further. This resulted in varying numbers of caregivers who responded to questions about what would improve/worsen their lives, and these numbers are summarised in Figure 8.

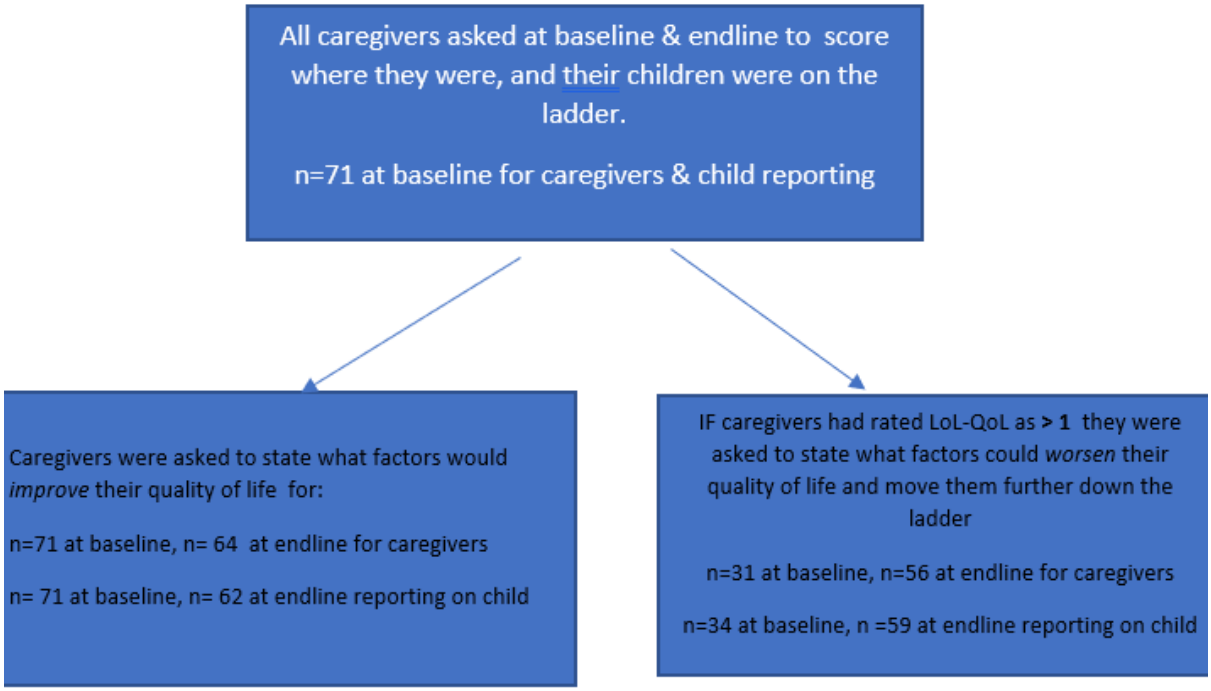


Figure 8 Flow chart illustrating number of caregivers who were asked additional questions

The decision was made not to use this tool directly with the children because the majority, (72%) of children were under five years with a mean age of 3.8 years (SD 2.69). Instead, caregivers were asked to report on 1) their own position on the ladder, and then 2) report on their children's position on the ladder.

Data were collected electronically using a tablet (Google Nexus 7) and the ODK software. The same respondents (primary caregiver) were re-interviewed 13-14 months later, within 1–2 months after completion of the last training session (endline).

Analysis

Data analysis on the global scores was conducted with Stata 13 (Stata, 2013).

In order to evaluate the change in LoL-QoL, statistical analysis of the scores were restricted to respondents who were included at both baseline and endline. Baseline LoL-QoL scores were negatively skewed. Therefore, median values were calculated, and a non-statistical test parametric test (Wilcoxon signed-rank) was used to compare baseline and endline scores. Change (baseline to endline) in LoL-QoL scores were normally distributed and therefore mean values were calculated. The open text data from all the respondents at baseline and endline were included in the analysis. A simple thematic analysis of the qualitative data in Microsoft Excel was conducted by the lead researcher (MZ). Table 5 provides an example of the coding for caregiver statements. Factors were coded as 1) caregiver factors 2) child factors or 3) family factors. After coding, the frequency distribution of the different factors reported was counted using Microsoft Excel and proportions were calculated as the percentage of caregivers who reported each reason.

Table 5 Thematic coding of Ladder of Life with example quotes

Coding theme	Example statement captured from caregiver*
Caregiver factors	
Caregiver health (*physical or emotional*) improves or deteriorates	*If my health improves* *[If I have] Happiness and peace of mind* *If I happen to have bad health* *If I keep getting weaker as a result of taking care of him*
Caregiver skills (*improvement in or not able to put in practice*)	*If I learn more ways to how best to take care of my child* *If I continue with what I have learnt from the training* *If we stop entirely with what we were taught to do with him.*
Financial challenges/ability or inability to work	*When I have money to trade.* *When I have the opportunity to work.* *If it continues that I spend all my money on my child.* *If finances do not improve after a while*
Child factors	
Child attends school	*If my child can attend school*
Child Cure	*[I get] A cure for my child*
Child Functioning e.g., related to whether child could sit/walk/crawl/talk	*If he can use his arms and legs* *If the child stops being able to walk* *If he is never able to walk well, talk, feed himself*
Child emotional health	*Child is happy*
Child health general	*When the child is healthy*
Child Independent	*When [V] is able to be independent*
Assistive Devices (availability of)	*If assistive device (tricycle) breaks down and if he doesn't receive the devices they requested*
Family factors	
Family Unity	*To have unity in the family*
Support for caregiving	*Help and support with [M]*

Results

Administration and completion of questionnaire

Overall, the research team reported that the tool was easy to administer. Translation of the question was simple and straightforward. The concept of a 'ladder' appeared to be understandable by interviewees, and there were no obviously noted problems in pointing to a position on the ladder scale. The process of selecting a 'score' was generally rapid. However, the explanation for what would improve or worsen QoL could take some considerable time if respondents started to engage in a longer narrative. Two caregivers refused to complete this question at baseline. The response of one caregiver who refused to give a score was, '*Only God knows'* and '*Only God can change her condition'*. Data from a further two caregivers were also absent from the data set, although it was unclear why. Therefore, at baseline the qualitative information gathered was from 71 caregivers.

Distribution on LoL-QoL score

Overall, the caregiver LoL-QoL median score was 2.0 at baseline and 5.0 at endline. The caregiver-reported child LoL-QoL scores median was 1 at baseline and 5 at endline. As shown in Figure 11 and there was a significant increase in the LoL-QoL scores from baseline to endline for both children (median of 1 at baseline to 5 endline) and caregiver (median of 2 and baseline and 5 at endline), $p<0.0001$). On average, scores increased by 2.7 for children and 1.9 for caregivers.

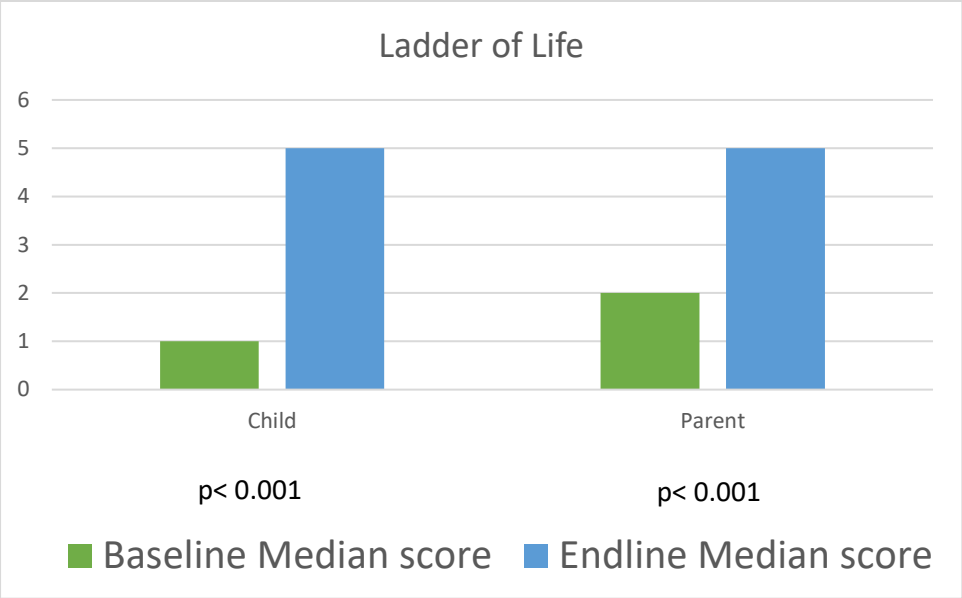


Figure 9: Median changes in LoL-QoL score

Table 6 Median changes in LoL-QoL score

	Baseline Median score (IQR)	**Endline Median score (IQR)**	**P-value***	**Mean change (95%CI)**
Child	1 (2)	5 (3)	P<0.001	+2.7 (2.1-3.2)
Parent	2 (4)	5 (5)	P<0.001	+1.9 (1.3-2.5)

* Wilcoxon signed-rank comparing baseline and endline scores; NG: Baseline data were skewed and therefore median scores and non-parametric statistical test were used. Change scores were normally distributed and therefore mean values were calculated.

The overall distribution of baseline and endline scores for caregiver and child are shown in Figure 10 and Figure 11 respectively. At baseline the response distributions were negatively skewed, with 36/71 (50%) caregivers scoring level 1 for their own QoL score at baseline (i.e. they felt they had '*the worst possible life'*) and 39/71 (55%) caregivers scoring level 1 for their child's QoL at baseline. In contrast at endline, the scores were more evenly distributed.

Figure 10: Distribution of caregiver LoL-QoL score at baseline and endline

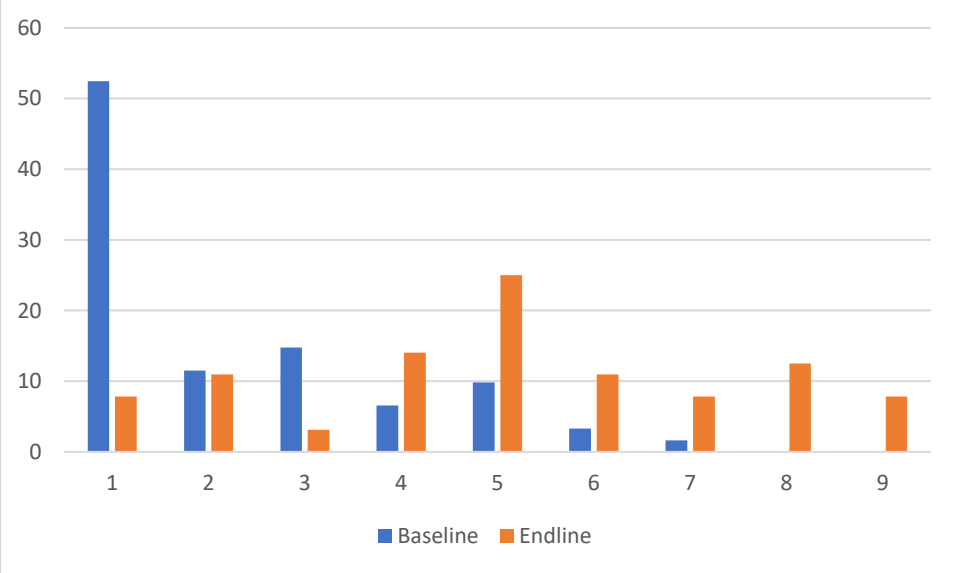


Figure 11: Distribution of child LoL-QoL scores at baseline and endline

Factors which will improve caregiver LoL-QoL

There were several key factors reported for contributing to improved caregiver QoL. The key themes were similar at baseline and endline, but with a change in emphasis at the different stages, as detailed in Table 7. At baseline, the most common factor that caregivers reported could improve QoL were an improvement in the child's functioning (33%). Specifically, this most commonly related to wanting to see the child stand and walk. Finding a cure for their child (29%) was the second most common reason given, and financial reasons accounted for 17% of responses.

Table 7 Factors which can improve caregiver LoL-QoL at baseline and endline.

Reasons for caregiver QoL life to improve*	**% baseline**	**% endline**
Caregiver /family factors		
Financial situation improves/ability to work	21%	39%
Caregiver skills improve	-	6%
Support for caregiving e.g. from family	8%	5%
Caregiver health improves	-	3%
Child factors		
Child functioning improves/continues to improve	39%	44%
Finding a cure	35%	2%
Child attends school	6%	14%
Child's improved emotional health	1%	-
Child behaviour	-	2%
Assistive devices provided	-	2%
Child needs are met	-	1%
Child is independent	1%	-

* *Total percentage is > 100% as some caregivers reported two reasons*

At endline, continued improvement in the child's functioning, again largely about improvements in physical functioning, and the ability to sit, walk, and stand, remained a consistent factor that could improve QoL, reported by 44% of caregivers. Improvements in the financial situation of the caregiver was the next most important factor (32%) and

included reasons such as the caregiver being able to return to work, having some capital to be able to trade, and having time free from caregiving so that they were able to work. The main difference in responses between the two time points was that by endline, '*finding a cure' f*or their child was only reported by one caregiver only (1%), compared to 35% at baseline.

Factors which contribute to a lowering of caregiver LoL-QoL

Data on factors which contributed to 'moving further down the ladder' were collected from 31 caregivers at baseline, and 56 caregivers at endline. The remaining caregivers in the sample had already stated that they were at 'level 1' of the ladder, and thus QoL could not deteriorate further.

There were several key themes identified for contributing to a decrease in caregiver LoL-QoL score and these are detailed in Table 8. These factors very much mirrored those that would improve their lives. At baseline, the most common factor given was a deterioration in the general 'condition' or 'functioning' of the child (64%). For example, '*if there is no change in the child's condition*', or '*If K is not able to walk*', '*if she is not able to crawl or walk*' , '*If [she] is not able to sit up and walk*'. This contrasted to 27% of caregivers at endline. At endline there were some changes in response distribution. Child illness was the most commonly reported reason for LoL QoL to deteriorate, increasing from 9% at baseline to 39% at endline. Financial factors were the second most common reason given at endline for a deterioration; a reason given by 32% caregivers, in comparison to 24% at baseline. The third

most common reason was a deterioration in the general 'condition' or 'functioning' of the child, although this was only reported by 27% at endline compared to 64% at baseline.

Table 8 Factors that contribute to a lowering on caregiver LoL-QoL

Factors which will worsen Caregiver LoL-QoL *	**% Baseline**	**% Endline**
Caregiver/family factors		
Financial challenges /caregiver inability to work	24%	32%
Caregiver skills – not put into practice	-	2%
Stigma	3%	-
Lack of support for caregiving/poor support from family	3%	5%
Worsening caregiver/family health	3%	5%
Child factors		
Child illness	9%	39%
Child's condition/functioning does not improve/continue to improve	64%	27%
Assistive devices (Lack of)	-	2%
Child cure (if cannot find a cure)	3%	-

**Caregivers were not asked what would worsen their QoL, and 'move down the ladder', if they had already reported that they had the 'worst possible life' and were at level 1.*

Factors which improve the child LoL-QoL score life

In the following sections I report on the caregiver-reported assessment of factors which impact on the child QoL. As a result of the young average age of the child, we asked parents to report on their child's LoL-QoL, and results are shown in Table 9. Overall, improvements in functioning of the child were the key reason given for improving quality of the child's life at both baseline (53%) and at endline (63%). This included, for example, their ability to stand, walk or talk.

Table 9 Caregiver-reported factors that will contribute to improving child LoL-QoL

Factors which will improve Child QoL	% Baseline	% Endline
Caregiver factors		
Caregiver skills - continue to apply training	-	8%
Caregiver's reduced stress	1%	-
Improvement in support		3%
Child factors		
Child is cured	34%	5%
Improvement in child functioning (e.g. able to walk)	55%	63%
Child attends school	4%	17%
Child health (stays the same or improves)	3%	8%
Assistive device (improved access to)	1%	2%
Social participation e.g. my child can play with others	-	2%
Other	3%	10%

A difference observed across baseline and endline were '*finding a cure'* for the child, which was the second most common reason given at baseline (34%) compared to only 5% at endline. A second difference was their child being able to attend school, reported by 17% of caregivers at endline, compared to only 4% at baseline.

Overall, across both baseline and endline, caregivers did not report on their child's QoL improving as a result of improvements in the child's emotional health, or on improved social participation of the child.

Factors which will contribute to a lowering of child LoI-QoL

In terms of understanding what would lead to poorer quality of life for their child in the future, the following key themes are summarised in Table 10. The main reason given for a deterioration in the child's QoL at baseline was if the child's condition did not improve (53%), and the comments largely referred to child functioning, such as not being able to walk or sit. This compared to 26% at endline. In contrast, the main reason given for lowering of LoL-QoL at endline was if the child was to become ill, reported by 53% of caregivers.

Again, overall, poor emotional health and social participation of child were largely absent as factors given which might contribute to a worsening of the child's LoL-QoL.

Table 10 Parent report factors which contribute to a lowering of child LoL-QoL

Factors which will worsen Child LoL-QoL	**% at baseline**	**% at endline**
Caregiver/family factors		
Deterioration in caregiver skills	-	7%
Finance	6%	7%
Lack of support in family	3%	5%
Lack of access to assistive devices	-	5%
Child factors		
Child's condition does not improve	53%	19%
Child illness	26%	53%
Child cannot attend school	-	2%
Child has no friends	3%	-
Child is unhappy	6%	-
Other	4%	2%

Discussion

Overall, in terms of feasibility and acceptability of using the tool, the data collectors found the LoL-Qol measure was easy to translate and administer. The scoring process was relatively simple, and during piloting the scale was easier for the caregivers to understand, in comparison to the *PedsQL™* scale. The latter was found to need more explanation about its different categories, and difficulties in the translation into local terms as detailed in **Chapter four** (Section on translation of tools). There were limited missing data with only two respondents not wanting to offer a score at baseline. Translation of the question was simple and straightforward. The concept of a 'ladder' and its scale appeared to be understandable by the interviewee, with positive feedback during the piloting phase, with no noticeable difficulties in pointing to a position on the scale. The significant improvement in scores at endline, which concurs with the change seen using the *PedsQL™* indicates that it is a sensitive tool that is responsive to change.

The caregiver narrative which accompanied the scoring sometimes took considerable time, as some participants saw this as an opportunity to share their 'story'. However, the counterbalance was that the inclusion of the open-ended questions alongside the scoring on the LoL-QoL also contributed to our understanding of caregiver rating of their QoL in a number of ways, which are further discussed below. One possible suggestion is to record this component of the conversation so that it could be more accurately analysed. The data provided on '*what would lead to a worsening'* of the LoL-QoL score very much mirrored the data on '*what would improve LoL-Qol'*. This was an extra question added to the LoL-QoL version in this study that required additional time to implement and to analyse the subsequent data. In reviewing the data, I would argue that this question does not further

add to our understanding of the issues and recommend removing it in a future iteration of the tool.

The data collector records a written summary of the respondents' answers to the open questions (rather than recording verbatim). This brings a potential bias, especially when long narratives are given by the respondents; what is recorded might be influenced in some way by the collectors' own attitudes and perceptions, as well as their ability to succinctly summarise the data into a key reason/reasons. Social desirability bias in the caregiver reporting may have occurred, with caregivers wanting to demonstrate a strong need for the programme at the start, and to demonstrate their appreciation at the end.

In terms of the results, at the beginning of the programme, caregivers reported extremely low scores for their Lol-QoL. This finding is consistent with the findings from the *PedsQL™* measure, as reported in **Chapter five (Paper 1)**, and also reflects the qualitative data collected at baseline. The distribution of LoL-QoL scores is also consistent with another study in Ghana which used the Cantril ladder with 25 caregivers of children with physical and intellectual disabilities. In that study the median score was '0' on a ladder with a scale of 0-10 (Den Besten et al., 2016). This same study also reported that the score is far below the average score of 5.09 for the general population of Ghana (Helliwell JF et al., 2013) and suggests a lack of ability to meet basic needs such as shelter and food, and indicative of poor mental health.

Low QoL scores align with a wider body of literature on caregiver wellbeing and QoL in LMIC, as reported in **Chapter two**. For example, a systematic review on caring for a child

with cerebral palsy in low-, middle-, and high-income countries found evidence of high levels of stress and depression, and that caregivers of children with a disability were consistently found to have poorer QoL compared to caregivers who did not have a child with a disability (Pousada et al., 2013).

It was of interest to note that a key factor which caregivers identified would improve their own lives at the beginning of the programme was '*finding a cure'* for their child. Notably, this contrasted with only one caregiver reporting on this by the end of the programme. A number of explanations have been posited for why '*finding a cure'* is a common theme in studies with caregivers of children with disabilities (as explored briefly in the literature review in **Chapter two**). For example, other studies have suggested the constant searching for a cure may in part be driven by pluralistic beliefs, but this behaviour is also likely to be driven by the lack of diagnosis, lack of information, and persistent challenges experienced in accessing health and rehabilitation services treatment (Nyante and Carpenter, 2019, Mkabile et al., 2021, Gona et al., 2011). In this study, the observed change in caregiver understanding that there is not a 'cure' for their child, but that they can improve their child's situation. This ties in with the interpretation that pluralistic beliefs around disability do fluctuate, as families adopt a pragmatic approach, as they seek to make sense of, and improve, their child's situation (Bunning et al., 2017).

In this study, the change in responses from baseline to endline also suggest an important pivot in focus, away from endless, exhausting, and expensive searching for a cure, towards

improving care and support for their child's development. It may also suggest a change in attitudes and the feelings of 'hope' for their child's future, with increased acceptance of their child, as a result of seeing even small changes in the child's condition through their engagement in the programme. This idea is further elaborated in **Chapter seven**.

Another key factor identified through this LoL-QoL tool was the role of the caregiver's socio-economic situation in impacting upon QoL. Common issues identified that caregivers said would improve their QoL were the ability to return to work, and/or seed capital to start a business. This ties in with findings from other studies on the indirect costs of caregiving, including the inability to return to work or not having enough time for income-generating activities (Kyerematenge et al., 2019, Oti-Boadi, 2017, Mkabile et al., 2021). Few studies on caregiving have examined the impact of the spiral of poverty on caregiver wellbeing (Namazzi et al., 2020). The impact is particularly exemplified in a study with caregivers in South Africa, where '*profound distress'* and a *'sense of failure'* was the result of the relentless challenges of poverty experienced (Van der Mark et al., 2019a). These findings emphasise, again, the importance of understanding the caregiver-child dyad relationship within the wider socio-ecological system, and of the combined interacting factors, specifically here the role of poverty. This was better captured using the LoL-QoL tool, and yet was not captured by using the *PedsQL™* alone. The way poverty interacts with caregiver empowerment and stigma is explored in the following chapters, and the implications of these different strands of the study are further explored in **Chapter ten**.

Another change at endline, albeit a small one, was that more caregivers reported on the importance of their child being able to attend school. This may reflect greater awareness, as

a result of the programme, on the rights of their child to attend school, combined with increased expectations for their child and/or improved understanding of the capabilities of their child. Whist this reflected awareness of the importance of participation in school, it was noted that the importance of the child's wider social participation and inclusion in family and community activities was not reported on. For example, only one parent commented on an improved life for their child if they were able to '*play with friend*s'. This might be because of how the caregivers interpreted the question. It might also suggest the need to review the training programme and the need for a greater emphasis on the central importance of promoting participation and inclusion. Whilst this is included as a cross cutting issue in the programme, it is often implicit, and may need more emphasis. This would also bring the programme into closer alignment with the ICF disability model which emphasises the important role of participation in the interaction with other factors (World Health Organisation, 2001).

Finally, the data illustrated the value of using different QoL tools, and some of the strengths and weaknesses of the LoL-Qol versus the *PedsQL™*. One key criticism of a single global score, such as the LoL-QoL, is that it does not adequately capture the multi-dimensionality of Qol and may be less reliable than other multi-question or battery measures (Fayers and Machin, 2013, Gill, 1995), such as the *PedsQL™*. However, I would argue, based on our findings, that the provision of the additional qualitative data that complemented the single global score, helped illuminate the participant interpretation of the question. It can capture the multi-dimensionality of their experience, as well as allowing them to 'weigh' the most important dimensions of relevance to them, rather than questions being intrinsically

weighted within the measure. The LoL-QoL was easy to use and translate, whilst as detailed in **Chapter four**, considerable time needed to be invested in the forward and back translation and cognitive validation of the *PedsQL™.* However, advantages of the *PedsQL™* include that it has been internationally tested for reliability and validity (Varni et al., 2004, Scarpelli et al., 2008, Ab Rahman et al., 2011) and tailored specifically to issues of caring for children with a chronic condition, which is a real strength of the tool.

In practice, the findings demonstrate how, for example, by combining a generic simple measure such as the LoL-QoL with the more tailored *PedsQL™*, a holistic picture of caregiver wellbeing is provided. This combination better aligns with the WHO definition of QoL detailed above (WHOQOL group, 1995).

Further implications of the findings from this tool for the programme, and for future programme development, are explored in **Chapter ten**.

Limitations

In this study, caregivers were asked to report on their child's LoL-QoL. Other studies have shown that parents and caregivers often report poorer QoL than their children; there is often agreement between a child and parent score on physical aspects of functioning, but less agreement on emotional or social elements of QoL scores (Eiser and Morse, 2001). This should be a consideration when reviewing this data. It also suggests that it would be valuable to test out this tool in future with older children and to compare their responses with a parent proxy report.

Conclusion

In conclusion, the LoL-QoL is a simple tool, easy to use, and offers one global score for QoL. The qualitative data captured provides a useful snapshot of a key factors in the lives of caregivers which impact on wellbeing from their perspective. It is useful in complementing the health-related *PedsQL™* score family impact module and offers a more holistic and contextual picture of caregiver QoL, which is in line with the WHO definition of QoL. The LoL-QoL scores for caregivers in this study were exceptionally low and suggested that even basic needs were not being met at baseline. There was a significant improvement in the QoL score at endline which indicated a positive impact of the programme. However, the scores were still low, and most notably, in using this tool, it was clear that financial factors were a key constraint on caregivers in the Ghana setting.

Chapter Seven Understanding the impact on the wellbeing of caregivers (Paper 2)

Photo 6 Grandmother providing consent during the first visit

In this chapter **(paper two),** I explore caregiver wellbeing from an analysis of the qualitative longitudinal data. This chapter addresses Study Objective 2, '*To explore the pathways of change for caregivers participating in the programme, with a focus on understanding the impact on caregiver wellbeing'.*

The chapter details the in-depth interviews conducted with 18 families during the course of the programme, at up to three time points. Firstly, I detail the experience of caregivers at the outset, prior to the start of the programme. I then report on changes after 15 months; two months after completion of the programme. The focus in this paper is on the salient

changes reported from the caregiver's perspective, and how that contributes to caregiver wellbeing.

Through the use of a longitudinal design, I detail the complex and dynamic range of factors which shape the caregiver engagement with the programme over time. These factors are drawn from different ecosystem layers of the caregiver-child dyad, with a focus on the micro and macrosystem. I explore the particularly salient changes at the level of the individual caregiver, with important issues such as *developing hope*, and *reduced feelings of self-stigma*. This appears to particularly develop from improved understanding of their child's condition, sharing experiences with others, and appreciating they are not alone. The rich contextual detail is valuable in understanding how both factors *within* one ecosystem, as well as *across* microsystems, interplay to impact on the caregiver-child dyad.

The influence of interacting factors in the lived experience of the caregiver is explored, in terms of the different identities that caregivers hold, is reflected upon, and the notion of the 'empowered' caregiver as the main agent of change is very briefly critiqued. The issues of caregiver empowerment and the experience of stigma related to being a caregiver of a child with a disability is first introduced here. These two concepts are then further interrogated in **Chapters eight** and **nine**.

LONDON SCHOOL of HYGIENE &TROPICAL MEDICINE

London School of Hygiene & Tropical Medicine
Keppel Street, London WC1E 7HT

T: +44 (0)20 7299 4646
F: +44 (0)20 7299 4656
www.lshtm.ac.uk

RESEARCH PAPER COVER SHEET

Please note that a cover sheet must be completed for each research paper included within a thesis.

SECTION A – Student Details

Student ID Number	461745	**Title**	Ms
First Name(s)	Maria Anne		
Surname/Family Name	Zuurmond		
Thesis Title	Understanding the lives of caregivers and evaluating a support programme for caregivers of children with disabilities: lessons learnt from Ghana		
Primary Supervisor	Janet Seeley		

If the Research Paper has previously been published please complete Section B, if not please move to Section C.

SECTION B – Paper already published

Where was the work published?	Child Care Health and Development		
When was the work published?	March 28 2018		
If the work was published prior to registration for your research degree, give a brief rationale for its inclusion	No		
Have you retained the copyright for the work?*	**Yes**	Was the work subject to academic peer review?	**Yes**

*If yes, please attach evidence of retention. If no, or if the work is being included in its published format, please attach evidence of permission from the copyright holder (publisher or other author) to include this work.

SECTION C – Prepared for publication, but not yet published

Where is the work intended to be published?	
Please list the paper's authors in the intended authorship order:	

Stage of publication	Choose an item.

SECTION D – Multi-authored work

For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)	Conceptualisation, design, led on investigation in the field and data analysis project administration, writing original draft and final editing

SECTION E

Student Signature	Maria Zuurmond
Date	08/12/2020

Supervisor Signature	Janet Seeley
Date	8th December 2020

Received: 28 March 2018 | Revised: 9 July 2018 | Accepted: 12 August 2018

DOI: 10.1111/cch.12618

ORIGINAL ARTICLE

WILEY

A support programme for caregivers of children with disabilities in Ghana: Understanding the impact on the wellbeing of caregivers

Maria Zuurmond[1] | Gifty Nyante[2] | Marjolein Baltussen[3] | Janet Seeley[4] | Jedidia Abanga[5] | Tom Shakespeare[6] | Martine Collumbien[7] | Sarah Bernays[8]

[1] International Centre for Evidence in Disability, London School of Hygiene and Tropical Medicine, London, UK

[2] University of Ghana, Accra, Ghana

[3] CBM East Africa Advisor Community Based Inclusive Development, Kigali, Rwanda

[4] London School of Hygiene and Tropical Medicine, London, UK

[5] PCG-Health Coordination Office, Accra, Ghana

[6] Norwich Medical School, University of East Anglia, Norwich, UK

[7] Faculty of Public Health and Policy, London School of Hygiene & Tropical Medicine, London, UK

[8] Sydney School of Public Health, Sydney Medical School, London School of Hygiene and Tropical Medicine, London, UK

Correspondence
Maria Zuurmond, Research Fellow, International Centre for Evidence in Disability, London School of Hygiene and Tropical Medicine, London, UK.
Email: maria.zuurmond@lshtm.ac.uk

Abstract

Background: Four fifths of the estimated 150 million children with disability in the world live in resource poor settings where the role of the family is crucial in ensuring that these children survive and thrive. Despite their critical role, evidence is lacking on how to provide optimal support to these families. This study explores the impact of a participatory training programme for caregivers delivered through a local support group, with a focus on understanding caregiver wellbeing.

Methods: A qualitative longitudinal study was conducted to investigate the impact of a training programme, "getting to know cerebral palsy," with caregivers on their wellbeing. Eighteen caregivers, from four districts, were interviewed up to three times over 14 months, to assess impact and the reasons for any changes.

Results: Low levels of knowledge, high levels of stigma, physical and emotional exhaustion, and often difficult family relationships with social exclusion of the child and caregiver were common themes at the outset. Caregivers struggled to combine their caring and economic activities. This was exacerbated by the common absence of the father. Two months after completion of the training, their reported wellbeing had improved. The reasons for this were an improved understanding about their child's condition, positive attitudinal change towards their child, feelings of hope, and through the group support, a profound realisation that they are "not on their own." While relationships within the family remained complex in many cases, the support group offered an important and alternative social support network.

Conclusions: This study illustrates the many benefits of a relatively simple caregiver intervention, which has the potential to offer a mechanism to provide sustainable social support for caregivers and children with cerebral palsy. Any future programme needs to also address more structural issues, including stigma and discrimination, and strengthen approaches to family engagement.

KEYWORDS

caregiver, cerebral palsy, child disability, evaluation, Ghana, wellbeing

 © 2018 John Wiley & Sons Ltd

1 | BACKGROUND

Globally, the most common cause of childhood physical impairment is cerebral palsy (Donald et al., 2014), estimated at 2 to 2.5/1,000 live births globally. Children with cerebral palsy may have complex care needs, due to sensory, intellectual and communication impairments, and possibly epilepsy, in addition to impaired motor function. And yet basic services available for them in low and middle income settings (LMICs) are frequently weak or absent (Donald et al., 2015). The new global child health agenda shifts the debate from survival to thriving, thus underlining the need to support both child and family (Colver, Fairhurst, & Pharoah, 2013; den Besten, Cornielje, Cornielje, & Botwey, 2016; Rosenbaum, 2011; Yousafzai, Lynch, & Gladstone, 2014).

Research in LMICs highlight that caregivers of children with disabilities frequently experience a range of difficulties: high levels of stress, anxiety, depression, and physical exhaustion, stigma, and discrimination often shaped by traditional beliefs and poverty (Bunning, Gona, Newton, & Hartley, 2017; Dambi, Jelsma, & Mlambo, 2015; Gona, Mung'ala-Odera, Newton, & Hartley, 2011; Nakamanya, Siu, Lassman, Seeley, & Tann, 2014; Sandy, Kgole, & Mavundla, 2013; Tilahun et al., 2016). These can result in poorer caregiver quality of life, compared to caregivers of non-disabled children (Dambi, Chivambo, Chiwaridzo, & Matare, 2015; Zuurmond, Mahmud, Polack, & Evans, 2015), as well having a negative impact on parenting (Barnett, Clements, Kaplan-Estrin, & Fialka, 2003).

Despite high levels of need, there is a paucity of evidence on the efficacy of interventions for families of children with disability in LMICs (Donald et al., 2015; Donald, Samia, Kakooza-Mwesige, & Bearden, 2014; Yousafzai et al., 2014). Parent focussed interventions have shown some positive benefits, some of which have been mediated through support groups, but these studies have largely been in high income settings (Masulani-Mwale, Mathanga, Kauye, & Gladstone, 2018). Fewer studies in LMICs exist but have described some positive outcomes of training parent groups (Adams et al., 2011; McConachie et al., 2000; McConkey, Mariga, Braadland, & Mphole, 2000). With a view to strengthen future interventions, this study explores the impact of a community-based parent support group training in Ghana, with a focus on understanding improvements in caregiver "quality of life" and "wellbeing." These two terms are often used interchangeably (Camfield, Crivello, & Woodhead, 2009; Camfield & Skevington, 2008). Early theories on quality of life and wellbeing focussed on individual achievement of happiness and satisfaction (Andrews & Withey, 1976; Bowling, 1999, 2014) or on an individual's capability to pursue their goals (Deneulin & McGregor, 2010; Sen, 1993). The importance of social relationships and understanding of the collective character of human wellbeing came later (Deneulin & McGregor, 2010; Ruta, Camfield, & Donaldson, 2007), and our study draws upon this theoretical perspective.

For a holistic, relational, and contextual understanding of people's lives, we adopt a longitudinal qualitative design, drawing upon the socioecological model (Centers for Disease Control, 2015), to study the interplay of various factors at different levels of a social system (family, support group, and community) affecting changes in the caregiver.

Key messages

- Cerebral palsy is the most common cause of childhood physical impairment, and these children will often have complex care needs over their lifetime.
- A participatory training programme targeting caregivers in a support group setting can offer many important benefits, including improved understanding, confidence and self-esteem, and a reduction in self-blame resulting in improved care for the child.
- A support group appears to offer an important social safety net for caregivers often socially excluded in their own communities.
- There is an intersectionality of gendered caregiving, disability, and poverty, and a strengthened approach to more structural issues, including stigma and discrimination, and poverty reduction strategies is required.
- Families play an important role in caregiving, and we need to explore how we can better harness their capacity, including the engagement of fathers.

2 | METHODOLOGY

2.1 | Intervention and theory of change

Seventy-five caregivers were invited to join a support group in one of the eight districts, with an average group size of 8–10 caregivers. Each group met monthly for an average of 4 hours, to cover the modules in "Getting to Know Cerebral Palsy" (LSHTM & Hambisela, 2013) as outlined in Figure 1.

The training was participatory and based on principles of adult learning theory (Knowles, 1984) to promote critical thinking, problem solving, and peer support. Core to the theory of change (ToC) was empowering the caregiver to improve care and support for their child, including an understanding of their rights, additionally, to share their learning with family members who in the West African setting have an important role in child-rearing (Goody, 2005)

In total, 13 facilitators underwent a 1-week master training and were paired to deliver the getting to know cerebral palsy training to each group. Each pair consisted of a physiotherapist/physiotherapy assistant and a primary health worker. Additionally, the facilitator/s made short monthly home visits to provide follow up on the training session and engage with other family members. Overall attendance at the programme was high with 92% of all families at endline having attended all of the training sessions.

2.2 | Participant selection

Caregivers were identified through the community-based screening programme for cerebral palsy, hospital records of children diagnosed with cerebral palsy in the last six months, and at one site additional

FIGURE 1 Outline of modules for parent support group training, available at http://disabilitycentre.lshtm.ac.uk/getting-to-know-cerebral-palsy/ [Colour figure can be viewed at wileyonlinelibrary.com]

screening was used to find sufficient local cases to run the group. Children had a confirmed diagnosis of cerebral palsy and were aged 18 months to 12 years, and caregivers had not attended any parent support group nor any regular physiotherapy with their child.

Four (out of eight) sites were then purposively selected for this qualitative study, ensuring a geographical spread, families of different socioeconomic status, and a mix of children according to gender, age (<6 and 6–12 years), and severity of cerebral palsy. Eleven families were selected in the first round, and following the death of three children, a further five families in the second round, and two more at endline. Interviews were conducted with 18 primary caregivers; seven were interviewed 3 times, five interviewed twice, and six interviewed once. Additionally, short opportunistic interviews were conducted with a secondary caregiver, at the time of the household interviews, in order to capture another perspective on caregiving within the family.

2.3 | Research design

This study was part of a larger pre- and postintervention study. The qualitative longitudinal research was undertaken with between April 2015 and June 2016 (see Figure 1), in which we used repeat waves of data collection to facilitate an exploration of the household context and how lives are shaped by the economic, cultural, and social norms (Dornan & Woodhead, 2015) in order to have a richer understanding of how the training programme worked in practice. The research questions addressed in this paper are to explore (a) in what ways the intervention impacted upon the caregiver wellbeing and (b) the change process that caregivers engaged in, in order to inform future strengthening of the intervention.

2.4 | Methods

Up to three in-depth interviews were conducted with caregivers as outlined in Figure 2. The aim of having interviews midway was to capture the caregiver journey through the programme. All interviews followed a similar structure, exploring understanding of the condition, the health and wellbeing of the child and caregiver, and networks of support including access to services. The midline and endline interviews additionally focussed on exploring their experience of the parent group and home visits and how their experiences of the intervention may have changed over time.

Interviews were conducted by a lead interviewer (White-British female MZ) and a local researcher (female Ghanaian GN), in four local languages with translation into English or into Twi. Interviews were conducted in the home setting; a "ladder of life" tool was used to explore caregivers' perceived quality of life, "0" being the first rung of the ladder and the worst possible life and "9" being the best top of the ladder and the best possible life (Crivello, Camfield, & Woodhead, 2009; den Besten et al., 2016). Photoelicitation, using photos taken of group activities, helped to reestablish rapport with the caregivers and stimulate more concrete discussions about the role of the parent support meetings and can be particularly useful in low-literate groups (Banks, 1995; Morrow, 2001). In advance of follow-up interviews, a short progress update was gathered about each child from the local facilitator, as well as group monitoring data, to tailor questions and probes to the family; for example, if the child was still malnourished, there was more probing about their experience with feeding and nutrition.

Ethics approval was obtained from the Noguchi Memorial Institute for Medical Research, University of Ghana and from the London School of Hygiene and Tropical Medicine. Informed written consent was obtained from all participating caregivers, with a signature or thumbprint. All children identified with malnutrition were referred for follow-up, and the CBM child protection policy was adhered to.

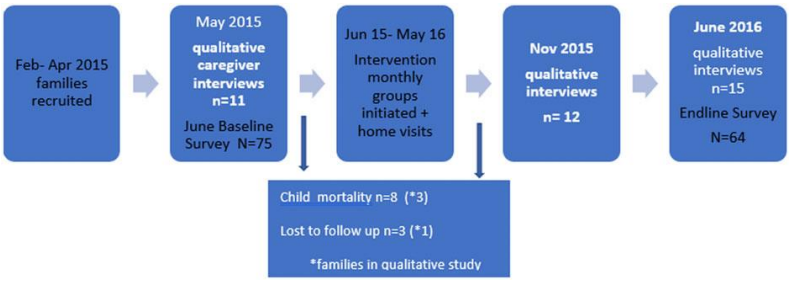


FIGURE 2 Flowchart showing research process [Colour figure can be viewed at wileyonlinelibrary.com]

2.5 | Analysis

All interviews were translated into English and transcribed. An interpretive approach underpinned the data analysis (Creswell, 2013), with emphasis on the caregiver's perspective. Two key stages of the analysis were conducted: a thematic analysis across all the interviews at each of the three phases of interviewing, using a priori themes from the ToC, and then an iterative process of developing more themes and subthemes as interviews were compared. A second stage analysis of the same data was a biographical case study analysis of each caregiver, offering a more holistic overview of their journey over the 6- to 14-month period, in line with guidance for longitudinal analysis (Creswell, 2013; J. Green & Thorogood, 2009). One researcher led the process (MZ), with ongoing discussion with the Ghana-based researcher (GN). Data were managed using NVIVO 12 software.

3 | FINDINGS

Key themes and subthemes were understanding of the condition with subthemes of diagnosis, traditional beliefs, acceptance, and hope; caring practices with confidence and behaviour change as subthemes; stigma with subthemes of exclusion/inclusion in different settings; mental health and peer support; and the cross-cutting theme of poverty.

3.1 | Our case study families

Fourteen caregivers were mothers, three grandmothers, and one a male cousin. Grandmothers were looking after the child because either the mother had died or had moved away. Most caregivers were traders or ran small businesses; the overall level of education was low, with only three caregivers having attended high school or tertiary education; and eight never having attended school. A socioeconomic index indicated that most families were economically very poor (See Table 1).

3.2 | Understanding of the condition

At baseline, a major theme was very low levels of understanding the condition: Almost no child had been given a medical diagnosis, despite repeated hospital visits. Families had commonly spent considerable time and resources "seeking a cure" for their child:

> *I first took her to the hospital; the doctor said she was lazy because of her weight. We were then referred to the physiotherapy unit and we were given some days to attend. ..... I got sick of going to the hospital every day. (Code 3339 Grandmother, granddaughter of 2 years)*

The absence of any medical diagnosis, combined with beliefs about disability being associated with witchcraft and family misfortune, meant that it was common to visit a range of traditional healers in seeking a cure, which included the use of various potent traditional medicines and sacrifices. Traditional beliefs were powerful and pervasive; a child with a disability was often not considered human. For example, in the south, the child could be described as "Asram"—a snake child or a river child. In the Frafra culture in the north, many children with a disability were described as "spirit children": "Her body is dead. She is not a human being" (Code 3339).

The programme improved the understanding about their child's condition, including the "humanisation" of their child which came with this knowledge, and a new vocabulary to describe their child's condition which avoided a reliance on stigmatising terms:

> *Oh, it has helped us. Some felt the children are "water children" (nsuo ba) but we got to know that it is caused by a brain injury (adwen mu yare-brain sickness) or when there is prolonged delivery (Code 1104 Mother with daughter of 18 months).*

With improved understanding came a shift in attitudes which included greater acceptance of the child and hope. Overall, when explaining why their lives had improved, the caregivers commented on the positive impact of seeing changes in their child's development, even small changes, as it gave them hope. As well as hope felt from seeing their own child's development, there were "collective" benefits from seeing other children improve. Groups often needed time to become established, so these positive reflections emerged more towards the end of the year intervention.

> *Being in a group has helped me a lot because sometimes you see children with the same problem and it gives you hope ... and I've see so many changes [in the group]. (Code 5560 to add Mother, son of 2 years).*

3.3 | Caring practice

Alongside the emotional and social strain of not having a medical diagnosis, the physicality of caregiving, associated with physical exhaustion was a recurrent theme at the baseline. Even when a caregiver lived within an extended family, they often received little support, so constant carrying and "backing" the child (carrying the child on their back) occurred, even when the mother was working. This became increasingly difficult for older and heavier children. Caregivers described frustration at not being able to put their child down as she would be crying. Some described how they were up in the night as their child did not sleep well. One mother wept as she explained the physical exhaustion of everyday caring for her 4-year-old son who had severe cerebral palsy: "My difficulty is my child he can't do anything for himself. I must do everything for him" (Code 55580).

By end line every caregiver reflected on both positive changes in their child and in their caregiving practice; changes in positioning of the child, in feeding practices, and understanding how to communicate with their child were popular changes described. In addition, several caregivers mentioned increased patience and less maltreatment of the child. This was noted as the most significant change observed by facilitators in their monthly monitoring of the groups.

> *When he used to eat, while crying, I used to beat him and when he was eating and turning here and there I didn't know how to take my time and feed him I just kept on feeding him. But when we went for the meeting they*

said whenever the child turns itself or is refusing to eat, we shouldn't do anything. (Code 3344 Mother, with 4-year old son).

Increased confidence associated with improved understanding of how to care for their child, interlinked with less self-blame for their child's disability, feeling valued in the group, and realising they had something to offer other mothers, appeared to link with improved self-esteem.

3.4 | Stigma and social inclusion/exclusion

At the baseline, interlinked with traditional beliefs was the stigma experienced by the child and caregiver in the home and in the community, including caregiver feelings of self-stigma and shame. The effects were profound and were a major reason given for why fathers had left, family members were unwilling to care for the child, the child and caregiver faced exclusion in home and community life, and why the child may be neglected. All caregivers were initially tearful in describing their lives, exemplified by one mother, left by the husband, and who was told by a community member that it would be better if her daughter had died: "Anytime I remember I grow angry and even weep. My husband came to tell me that in his family, no one has ever given birth to a child like this, so what I've given him is a curse" (N02). Initially, some mothers were less open at talking about aspects of their experience of stigma and shame, while other family members, such as grandmothers, were more open.

Although family structures varied across sites, from extended families in one compound to smaller units in peri-urban settings, caregiver isolation and social exclusion and an almost complete absence of a social support network were recurring themes. Fathers were almost completely absent from the household, whether because of separation or divorce, working away from home, and infrequent home visits (see Table 1). Asked whom she talked to when she had a problem, one mother replied:

I don't go anywhere I'm just in my room… I am not on good talking terms with my family members because of the problem [child's disability] and I am not close to the neighbours around, because of the child's condition too, so I do not draw near to them. (Code 5580 Mother, son of 4 years).

A widowed mother described how, despite being surrounded by her late husband's family, she had no one to leave the child with while she worked. Her daughter could "be lying down crying while people walking pass her … no one will touch her. They behave as if she is not human" (Code 3339).

By end line, the strongest recurrent theme was social inclusion from membership of the group "we have love for one another in the group," and the value of "not the only one" and "not on their own," which linked with reduced self-blame for their child's disability. By the end of the year, the group was commonly described as "like a family." The group offered an important support network that had been absent. The group offered each other support beyond the focus on their children.

The group was good because there was unity among us… Hum! I am alone sitting; I have no one to share my problem with… I know that I can share with them what my worry is, and there is understanding so they can support me. (case 3342 Mother with daughter of 12 years).

TABLE 1 Details of case study families

Caregiver relationship to child relation. M = mother, GM = GM	Caregiver occupation	Father living at home	Caregiver school level 0 = never attended, 1 = primary, 2 = junior high, 3 = senior high, 4 = tertiary	SES tertiles 1 = poorest
M	Trader	N	1	3
M	Trader	N—father moved out during the year, visits daily	3	3
GM	Manual work	N	0	2
M	Manual work	Dead	0	1
GM	Trader	N	1	2
M	Health worker	Y—father in prison at end line interview	4	2
M	Hairdresser	Y—works away from home regularly	2	1
M	Apprentice hairdresser	N—living separately in compound	0	2
M	Seamstress	N	0	2
M	Health worker	N—works away from home	4	3
GM	Trader (sells alcohol)	N	1	3
Cousin	Farmer	N	0	2
M	Trader	N	2	2
M	Farming	N	0	1
M	Farmer	N	0	1
M	Farmer	Y—polygamous, absent for last 7 months	0	1
M	Seamstress	Y—works away from home regularly	1	2
M	Apprentice seamstress	N	1	1

There was more limited progress in changes within the wider household dynamics. According to the ToC, the caregiver was expected to be the main agent of change within the family. There were examples of this, particularly within maternal families:

> *Before, I could not go to any place and leave the child behind. Anytime I went out, it was difficult for my mother to feed him. He used to vomit everything you feed him, but after the training, I also educated my mother and anywhere I go I come back to see him fed well. (9916 Single mum living with her own mother, son of 2 yrs).*

However, it was still common for caregivers to describe limited sharing of knowledge and of the training resources with other family members, and for secondary caregivers to not be aware of the training content. Most notably, carers often did not share when living with the husband's family when family relationships related to the child remained difficult. For example, one mother with a 3-year-old son with severe cerebral palsy, after the intervention had stopped beating her son through frustration, his feeding and nutrition had improved and he no longer cried through the night. She also positioned him correctly rather than just laying him on the floor. She said that learning how to communicate with him "has touched my heart." However, the family situation continued to deteriorate over the year: Her husband moved out while the mother-in-law looked for a second wife. His increasing lack of support meant that the mother struggled to pay for the child's health care, such as a hearing test. She did not feel able to share any learning within her husband's family.

The facilitator home visit was intended as one approach to engage with family members, and while all caregivers said they valued the fact that someone was prepared to visit them at their home, they commonly perceived it as "checking" that training was put into practice. The counselling element and engagement with other family members varied, but in general was limited, and monthly visits were sometimes prevented by a lack of transport and poor weather.

3.5 | Caregiver mental health

While at baseline the strong theme was of poor caregiver mental health, there did seem to be some improvements by the end of the intervention. Improved knowledge, understanding they were not alone, with a reduction in self-blame and feeling valued in the group, were factors which contributed to caregivers feeling emotionally better. Something as simple as a home visit could engender a sense of self-worth for a caregiver:

> *[Before the training] No one was coming to us. It has always been the two of us here alone, my mum and I and we were always crying. Now, from the meetings, we have all learnt a lot and this happens no more. (Case:9916, Mother of son, 3 years old).*

Other valued aspects of peer support from the group included peer learning, friendship, and a safe space to share experiences and offer psychosocial support, including encouragement.

> *Sharing of experiences is what I have enjoyed the most. Because when you have a problem you think your problem is greater than everyone else. We share ideas, sometimes there are things that they do with their children that we can do ourselves. (Code 5560).*

The importance of the group also included the relationship with the facilitators, whose home visits were valued, and who commonly played a brokering role to help them access services, such as renewing their child's health card or navigating the disability benefits system, for example, by accompanying them to the relevant offices. In some cases, this appeared to generate some dependency on the facilitator.

3.6 | Poverty

Poverty shaped the wellbeing of the majority of our caregivers and their ability to implement change from the training programme. The absence of fathers further contributed to a lack of resources, with no family accessing any social protection programmes at the outset of the training. Poor access to a livelihood was exacerbated if children were not in school, and/or the absence of family support, as described by one mother who carried her 5 year old daughter: "I put her on my back whilst I plant, when am tired I place her close to me so she can see me and not cry. What I could have done… When people need water for construction work, [I] carry her and get them the water." (Code 3339).

> *"Because of him [her son] I can't even work, and his father has rejected us. My family members too are not taking care of me. And I have so many problems in the world and it is very hard and difficult." (Code 5580).*

By end line, as a result of improved understanding about their rights, caregivers had accessed or were in the process of accessing the national disability fund (District Assembly Common Fund). As their child improved, and with access to assistive devices, some time was freed up for work or household chores, such as a simple sitting chair that permitted a caregiver to leave a child comfortably while they worked at home, or they took with them to the marketplace. There was more confidence in being able to leave a child with a family member, but these gains were sometimes small, and the need for improved access to livelihoods remained a key caregiver request for improving the quality of their lives. However, poverty also impacted on the ability to implement some of the training, such as caregivers acquiring knowledge about nutritious food and how to feed their child. Some struggled to provide any food at all for the family, including the child with a disability.

Overall, the data showed that the training and support groups were valued, with a positive impact on caregiver wellbeing. At the same time, it illustrated how complex life was for caregivers, with reduced earnings due to caring responsibilities, community stigma reducing access to community support, and all coalescing and exacerbating each other.

4 | DISCUSSION

In this paper, we explain why the overall caregiver quality of life improved as a result of engaging in the parent support training

programme (Zuurmond et al., 2018). Changes were mainly at the level of the individual, most notably improvements in caregiver understanding about her child's condition, reduced feelings of shame and self-stigma, and a shift in attitude towards their child, all of which was reflected in positive changes in care and support. The importance of building hope was an important component, promoting resilience in the face of long-term stress, where resilience is defined as a the ability to harness resources to sustain wellbeing (Southwick, Bonanno, Masten, Panter-Brick, & Yehuda, 2014). The process of parental adaptation and acceptance to having a child with a disability, important for parental wellbeing, has been documented in high income contexts (Barnett et al., 2003) and ties in with the apparent process of acceptance captured in this study, supported by meeting other caregivers.

We have also demonstrated the pervasive influence of societal stigma that shaped the outcomes in this Ghanaian context. The links between stigma and disability have been well evidenced (Van Brakel, 2006), and stigma has been has been shown to have complex and devastating effects on the health and welfare of individuals and families of children with disabilities, increasing stress and isolation (Bunning et al., 2017; S. E. Green, 2003; Nayar, Stangl, De Zalduondo, & Brady, 2014), and families of children with disabilities can play both a critical role in both perpetuating and reducing stigma (McConkey, Kahonde, & McKenzie, 2016). Stigma is a complex social construct (Goffman, 2009), and one useful type of categorisation of stigma is of "felt" or "self"-stigma, which is about feelings of shame or fear of rejection, and enacted stigma describing overt rejection and discrimination (Gray, 2002). Our study suggests important changes in caregiver self-stigma with positive changes in attitudes towards their child, which is notable given recent research in Ghana and Ethiopia with mothers of children with cerebral palsy and developmental disorders which documented high levels of caregiver self-stigma and shame for their child's condition (Nyante, Carpenter, & Igo, 2017; Tilahun et al., 2016). Yet there was more limited change outside of the dyad, with persistent discrimination. This highlights the need for a strengthened approach to addressing stigma and discrimination in any future design, an improved understanding of the environment in which the children and their caregivers interact, and the role of structural issues (Kippax, Stephenson, Parker, & Aggleton, 2013). A recent study with children who were visually impaired made a similar argument for understanding the nested environment of the child and caregiver in order to strengthen programmes (Gladstone et al., 2017).

In terms of understanding pathways of change, this study illustrated that group membership appeared to offer a valuable social support network, in the face of caregiver social exclusion. The importance of such support networks for the care of children with disabilities is recognised (WHO 2011), yet few studies have sought to evaluate different types of support networks and how and why they work to improve caregiver and child outcomes, especially in LMICs. Self-help groups for people with mental health conditions are increasingly used in low resource settings with evidence of their positive impact on both the person with the mental health condition and their caregiver (Cohen et al., 2012). Women's self-help groups have resulted in improved maternal and child health outcomes because of the participatory approach to knowledge development, a more critical consciousness of the issues, community involvement, and acceptability of the approach (Morrison et al., 2010; Tripathy et al., 2010). Membership of a group can have positive and protective functions (Durkheim, 1952), and "collective agency" can support individual agency (Kippax et al., 2013). Establishing a local parent support group, in which the members have increased responsibility for sustaining the network, may possibly offer a more sustainable mechanism to address some of the ongoing support needs.

Finally, we illustrate the intersectionality of poverty, gendered caregiving and disability, and how this shapes the caregivers' wellbeing and may constrain their ability to implement changes within their family and household as a result of the training. This study contributes to the call for a more nuanced understanding of the relationship between poverty and disability (Groce, Kett, Lang, & Trani, 2011). In addition to the struggle to combine livelihoods and caregiving, our study illustrates how the impact of caring for a child with a disability has other significant consequences, such as the departure of a husband, or being socially excluded, which compounds poverty. These effects, though profound, are not easily captured within standardised socioeconomic measures.

These effects can coalesce to damage the social credibility of the caregivers that undermines their efficacy as agents of onward change within the community. So, this context arguably dilutes the time, capacity, and influence that these caregivers may have in persuading others to adjust their own attitudes and caregiving practices.

These issues point to a shortcoming in the intervention design, that of the focus was on the "empowered" caregiver/s as the main agent of change. In practice, this was problematic given the intersectionality of factors that affected their lives: poverty, stigma and discrimination, and gender, all of which serve to deplete many caregivers' resources, as well as challenging their credibility to influence. The overall low levels of caregiver education may be another factor. It points to any future intervention needing to explore additional ways to engage with family and community, with improved harnessing of external agents of change, community and faith-based leaders, DPOs, and community health workers, such as the community-based health planning and services in Ghana (Nyonator, Awoonor-Williams, Phillips, Jones, & Miller, 2005). It may also be why external facilitators need to play an important brokering role at the start of such a programme, with a shift to greater parental leadership and building collective action, ensuring that facilitators have the skills in participatory approaches to facilitate this.

There are several limitations to this study. There was no follow-up after the intervention had finished, which would have added considerable value in understanding how sustainable these effects were. Collective action by the groups, including public engagement activities, occurred after the data collection phase, and it would have been of value to capture and understand that contribution, in any future study. The intervention is highly dependent on the quality of the facilitators and their ability to establish rapport with the caregivers. Future evaluations of similar interventions would benefit from including more observations of the group activities and home visit, including focusing on the relationships between facilitators and caregivers. Two thirds of our sample were 4 years old or below, and future research should explore the views of older children on the quality of their lives as a result of engagement in the programme.

5 | CONCLUSION

This study highlights several important benefits from a relatively simple intervention where caregivers join a local support group and engage with a participatory training programme, including positive changes in caregiver practices and peer-based social support. Our study has shown that this model has considerable potential and could feasibly be implemented with other families affected by other disabilities. However, we propose ways that the model could be further strengthened. The use of caregivers as facilitators or co-facilitators in the training may go some way to strengthening their role as agents of change. Such an approach is currently underway in Uganda for children with neurodevelopmental conditions (Martin et al., 2017) and in Brazil with children with Zika (Kuper, Smythe, & Duttine, 2018). The intervention is currently narrowly focussed on the relationship between the dyad of caregiver and child. To pursue a more transformative agenda, then the model needs to more effectively engage those around the caregiving dyad, including the broader family, husbands' relatives, and the community. This is vital to address stigma, discrimination, and ameliorate the effect of disability on household poverty. An extended intervention could also be adapted for the wider community: local personnel and leaders, such as teachers, primary health-care workers, and faith leaders, recognising the need to reduce the dependency on the caregiver as the agent of change and underlining of the importance of applying a gendered lens so there is not an additional burden to already overstretched female caregivers.

CONFLICT OF INTERESTS

The authors declare no conflict of interest.

ACKNOWLEDGEMENTS

We would like to thank additional members of our Ghana and international advisory board members including Dr. Norgrove Penny, Dr. Eben Badoe, Dr. Mel Adams, Dr. David O'Banion, Sandra Carsamer, Dr. Melissa Gladstone, Dr. Cally Tann, and Maxwell Akandem. Most importantly, we would like to thank all the participating families, especially the caregivers and children who participated in the programme and gave their valuable time for the researchers.

ORCID

Maria Zuurmond http://orcid.org/0000-0002-0347-0126

REFERENCES

Adams, M., Khan, N., Begum, S., Wirz, S., Hesketh, T., & Pring, T. (2011). Feeding difficulties in children with cerebral palsy: Low cost caregiver training in Dhaka, Bangladesh. *Child: Care, Health and Development*, *38*(6), 878–888.

Andrews, F. M., & Withey, S. B. (1976). *Social indicators of well-being: Americans' perception of quality of life*. The Management Group.

Banks, M. (1995). *Visual research methods*: Department of Sociology, University of Surrey.

Barnett, D., Clements, M., Kaplan-Estrin, M., & Fialka, J. (2003). Building new dreams: Supporting parents' adaptation to their child with special needs. *Infants & Young Children*, *16*(3), 184–200.

Bowling, A. (1999). Health-related quality of life: A discussion of the concept, its use and measurement background: The 'quality of life' By A. Bowling at http://info.worldbank.org/etools/docs/library/48475/m2s5bowling.pdf. Paper presented at the Adapting to Change Core Course, September 1999, accessed 2/01/2018.

Bowling, A. (2014). Quality of life: Measures and meanings in social care research.

Bunning, K., Gona, J. K., Newton, C. R., & Hartley, S. (2017). The perception of disability by community groups: Stories of local understanding, beliefs and challenges in a rural part of Kenya. *PLoS One*, *12*(8), e0182214.

Camfield, L., Crivello, G., & Woodhead, M. (2009). Wellbeing research in developing countries: Reviewing the role of qualitative methods. *Social Indicators Research*, *90*(1), 5–31.

Camfield, L., & Skevington, S. M. (2008). On subjective well-being and quality of life. *Journal of Health Psychology*, *13*(6), 764–775.

Centers for Disease Control. (2015). The social-ecological model: A framework for prevention at https://www.cdc.gov/violenceprevention/overview/social-ecologicalmodel.html.

Cohen, A., Raja, S., Underhill, C., Yaro, B. P., Dokurugu, A. Y., De Silva, M., & Patel, V. (2012). Sitting with others: mental health self-help groups in northern Ghana. *International Journal of Mental Health Systems*, *6*(1), 1.

Colver, A., Fairhurst, C., & Pharoah, P. O. D. (2013). Cerebral palsy Published online November 20, 2013 https://doi.org/10.1016/S0140-6736. *The Lancet*, (13), 61835–61838.

Creswell, J. W. (2013). *Research design: Qualitative, quantitative, and mixed methods approaches*Sage publications.

Crivello, G., Camfield, L., & Woodhead, M. (2009). How can children tell us about their wellbeing? Exploring the potential of participatory research approaches within young lives. *Social Indicators Research*, *90*(1), 51–72.

Dambi, J., Chivambo, G., Chiwaridzo, M., & Matare, T. (2015). Health-related quality of life of caregivers of children with cerebral palsy and minor health problems in Zimbabwe: a descriptive, comparative cross-sectional study. *Int J Sci Res Publ*, *5*.

Dambi, J., Jelsma, J., & Mlambo, T. (2015). Caring for a child with cerebral palsy: The experience of Zimbabwean mothers. *African Journal of Disability*, *4*(1).

den Besten, J., Cornielje, M. T., Cornielje, H., & Botwey, D. N. (2016). Supporting parents in caring for children with disability in Ghana. *Disability, CBR & Inclusive Development*, *27*(3), 87–101.

Deneulin, S., & McGregor, J. A. (2010). The capability approach and the politics of a social conception of wellbeing. *European Journal of Social Theory*, *13*(4), 501–519.

Donald, K. A., Kakooza, A. M., Wammanda, R. D., Mallewa, M., Samia, P., Babakir, H., … Shevell, M. (2014). Pediatric cerebral palsy in Africa where are we? *Journal of Child Neurology*. (Online First Version), http://jcn.sagepub.com/content/early/2014/2010/2001/0883073814549245

Donald, K. A., Kakooza, A. M., Wammanda, R. D., Mallewa, M., Samia, P., Babakir, H., … Shevell, M. (2015). Pediatric cerebral palsy in Africa where are we? *Journal of Child Neurology*, *30*(8), 963–971.

Donald, K. A., Samia, P., Kakooza-Mwesige, A., & Bearden, D. (2014). Pediatric cerebral palsy in Africa: A systematic review. *Seminars in Pediatric Neurology*, *21*(1), 30–35.

Dornan, P., & Woodhead, M. (2015). How inequalities develop through childhood: Life course evidence from the young lives cohort study. Innocenti Discussion Papers.

Durkheim, E. (1952). *Suicide: A study in sociology*. London & New York: Routledge & K. Paul.

Gladstone, M., McLinden, M., Douglas, G., Jolley, E., Schmidt, E., Chimoyo, J., … Lynch, P. (2017). 'Maybe I will give some help…. maybe not to help the eyes but different help': An analysis of care and support of children with visual impairment in community settings in Malawi. *Child: Care, Health and Development*, *43*(4), 608–620.

Goffman, E. (2009). *Stigma: Notes on the management of spoiled identity*. Simon and Schuster.

Gona, J. K., Mung'ala-Odera, V., Newton, C. R., & Hartley, S. (2011). Caring for children with disabilities in Kilifi, Kenya: What is the carer's experience? *Child: Care, Health and Development*, *37*(2), 175–183.

Goody, E. N. (2005). *Contexts of kinship: An essay in the family sociology of the Gonja of northern Ghana*Cambridge University press.

Gray, D. E. (2002). 'Everybody just freezes. Everybody is just embarrassed': Felt and enacted stigma among parents of children with high functioning autism. *Sociology of Health & Illness*, *24*(6), 734–749. https://doi.org/10.1111/1467-9566.00316

Green, J., & Thorogood, N. (2009). *Qualitative methods for health research*. (Vol (2nd ed.). London: Sage.

Green, S. E. (2003). "What do you mean 'what's wrong with her?'": Stigma and the lives of families of children with disabilities. *Social Science & Medicine*, *57*(8), 1361–1374.

Groce, N., Kett, M., Lang, R., & Trani, J.-F. (2011). Disability and poverty: The need for a more nuanced understanding of implications for development policy and practice. *Third World Quarterly*, *32*(8), 1493–1513.

Kippax, S., Stephenson, N., Parker, R. G., & Aggleton, P. (2013). Between individual agency and structure in HIV prevention: Understanding the middle ground of social practice. *American Journal of Public Health*, *103*(8), 1367–1375.

Knowles, M. (1984). The adult learning theory—Andragogy. Retrieved from https://elearningindustry.com/the-adult-learning-theory-andragogy-of-malcolm-knowles

Kuper, H., Smythe, T., & Duttine, A. (2018). Reflections on health promotion and disability in low and middle-income countries: Case study of parent-support programmes for children with congenital Zika syndrome. *International Journal of Environmental Research and Public Health*, *15*(3), 514.

LSHTM, & Hambisela. (2013). Getting to know cerebral palsy: Working with parent groups—A training resource for facilitators, parents, caregivers and persons with cerebral palsy retrieved from http://disabilitycentre.lshtm.ac.uk/2013/08/01/publication-of-getting-to-know-cerebral-palsy-manual/

Martin, K., Nalugya, R., Lassman, R., Sewagaba, M., de Silva, H., Musoke, M., … Nampijja, M. (2017). *P04 developing an early intervention programme for children at high-risk of neurodevelopmental impairment in Uganda*BMJ publishing group ltd.

Masulani-Mwale, C., Mathanga, D., Kauye, F., & Gladstone, M. (2018). Psychosocial interventions for parents of children with intellectual disabilities—A narrative review and implications for low income settings. *Mental Health & Prevention*, *11*, 24–32.

McConachie, H., Huq, S., Munir, S., Ferdous, S., Zaman, S., & Khan, N. Z. (2000). A randomized controlled trial of alternative modes of service provision to young children with cerebral palsy in Bangladesh. *The Journal of Pediatrics*, *137*(6), 769–776.

McConkey, R., Kahonde, C., & McKenzie, J. (2016). *Tackling stigma in developing countries: The key role of families*. London: Palgrave-Macmillan.

McConkey, R., Mariga, L., Braadland, N., & Mphole, P. (2000). Parents as trainers about disability in low income countries. *International Journal of Disability, Development and Education*, *47*(3), 309–317.

Morrison, J., Thapa, R., Hartley, S., Osrin, D., Manandhar, M., Tumbahangphe, K., … Pace, N. (2010). Understanding how women's groups improve maternal and newborn health in Makwanpur, Nepal: A qualitative study. *International Health*, *2*(1), 25–35.

Morrow, V. (2001). Using qualitative methods to elicit young people's perspectives on their environments: Some ideas for community health initiatives. *Health Education Research*, *16*(3), 255–268.

Nakamanya, S., Siu, G. E., Lassman, R., Seeley, J., & Tann, C. J. (2014). Maternal experiences of caring for an infant with neurological impairment after neonatal encephalopathy in Uganda: a qualitative study. *Disability & Rehabilitation(0)*, 1–7.

Nayar, U. S., Stangl, A. L., De Zalduondo, B., & Brady, L. M. (2014). Reducing stigma and discrimination to improve child health and survival in low-and middle-income countries: Promising approaches and implications for future research. *Journal of Health Communication*, *19*(sup1), 142–163.

Nyante, G., Carpenter, C., & Igo, S. (2017). Conceptualization of cerebral palsy: Experiences of caregivers of children with cerebral palsy in Ghanaian rural communities. *Numid Horizon International Journal of Nursing and Midwifery*, *1*(1), 19–28.

Nyonator, F. K., Awoonor-Williams, J. K., Phillips, J. F., Jones, T. C., & Miller, R. A. (2005). The Ghana community-based health planning and services initiative for scaling up service delivery innovation. *Health Policy and Planning*, *20*(1), 25–34.

Rosenbaum, P. (2011). Family and quality of life: Key elements in intervention in children with cerebral palsy. *Developmental Medicine and Child Neurology*, *53*(s4), 68–70.

Ruta, D., Camfield, L., & Donaldson, C. (2007). Sen and the art of quality of life maintenance: Towards a general theory of quality of life and its causation. *The Journal of Socio-Economics*, *36*(3), 397–423.

Sandy, P. T., Kgole, J. C., & Mavundla, T. R. (2013). Support needs of caregivers: Case studies in South Africa. *International Nursing Review*, *60*(3), 344–350. https://doi.org/10.1111/inr.12022

Sen, A. (1993). Capability and well-being. In M. Nussbaum, & A. Sen (Eds.), *The quality of life*. Oxford: Clarendon Press.

Southwick, S. M., Bonanno, G. A., Masten, A. S., Panter-Brick, C., & Yehuda, R. (2014). Resilience definitions, theory, and challenges: Interdisciplinary perspectives. *European Journal of Psychotraumatology*, *5*(1), 25338.

Tilahun, D., Hanlon, C., Fekadu, A., Tekola, B., Baheretibeb, Y., & Hoekstra, R. A. (2016). Stigma, explanatory models and unmet needs of caregivers of children with developmental disorders in a low-income African country: A cross-sectional facility-based survey. *BMC Health Services Research*, *16*(1), 152.

Tripathy, P., Nair, N., Barnett, S., Mahapatra, R., Borghi, J., Rath, S., … Sinha, R. (2010). Effect of a participatory intervention with women's groups on birth outcomes and maternal depression in Jharkhand and Orissa, India: A cluster-randomised controlled trial. *The Lancet*, *375*(9721), 1182–1192.

Van Brakel, W. H. (2006). Measuring health-related stigma—A literature review. *Psychology, Health & Medicine*, *11*(3), 307–334. https://doi.org/10.1080/13548500600595160

Yousafzai, A. K., Lynch, P., & Gladstone, M. (2014). Moving beyond prevalence studies: Screening and interventions for children with disabilities in low-income and middle-income countries. *Archives of Disease in Childhood*, archdischild-2012-302066, *99*, 840–848.

Zuurmond, M., Mahmud, I., Polack, S., & Evans, J. (2015). Understanding the lives of caregivers of children with cerebral palsy in rural Bangladesh: Use of mixed methods. *Disability, CBR & Inclusive Development*, *26*(2), 5–21.

Zuurmond, M., O'Banion, D., Gladstone, M., Carsamar, S., Kerac, M., Baltussen, M., … Polack, S. (2018). Evaluating the impact of a community-based parent training programme for children with cerebral palsy in Ghana. *PlOS ONE*, *13*(9), e0202096. https://doi.org/10.1371/journal.pone.0202096

How to cite this article: Zuurmond M, Nyante G, Baltussen M, et al. A support programme for caregivers of children with disabilities in Ghana: Understanding the impact on the wellbeing of caregivers. *Child Care Health Dev*. 2018;1–9. https://doi.org/10.1111/cch.12618

Chapter Eight: Illuminating the role of caregiver empowerment (paper 3)

Photo 7 Grandmother attending the facilitator training with her grandson

In this chapter **(paper 3),** I explore and illuminate the issue of caregiver empowerment as the caregivers engage with the programme. This chapter addresses Study Objective 3, *'To illuminate the role of caregiver empowerment as the caregiver engaged with the programme'.*

I begin the paper by reflecting on the relevance of empowerment for families of children with disabilities. An overview of the different definitions, concepts, and theories of empowerment, drawn from across different disciplines, is then summarised. Within my

study, the empowerment framework employed in the gender and development sector in the 1980s and 1990s is used to inform the analysis, whilst also drawing upon other conceptualisations of power.

The challenges in the operationalisation of empowerment, and specifically what it means in practice for caregivers and families of children with disabilities is reflected upon, and the dearth of literature which examines this. This paper aims to provide some empirical data on caregiver empowerment within a programme.

In addition to detailing a thematic analysis of the longitudinal qualitative data, I present three in-depth case studies to better illustrate the complexity of changes over time for individual caregivers. I offer a more nuanced understanding of the empowerment journey of the caregivers, explore the changes in different dimensions, the non-linear nature of the journey especially when lives can be very fragile, and facilitators and impediments to the reorientation of power. Finally, I argue for the need for the programme to place less emphasis on individual agency, and instead, permeate wider layers of the socio-ecological system as well as better address macro/structural issues.

London School of Hygiene & Tropical Medicine
Keppel Street, London WC1E 7HT

T: +44 (0)20 7299 4646
F: +44 (0)20 7299 4656
www.lshtm.ac.uk

RESEARCH PAPER COVER SHEET

Please note that a cover sheet must be completed for each research paper included within a thesis.

SECTION A – Student Details

Student ID Number		**Title**	Ms
First Name(s)	Maria Anne		
Surname/Family Name	Zuurmond		
Thesis Title	Understanding the lives of caregivers and evaluating a support programme for caregivers of children with disabilities: lessons learnt from Ghana		
Primary Supervisor	Janet Seeley		

If the Research Paper has previously been published please complete Section B, if not please move to Section C.

SECTION B – Paper already published

Where was the work published?	Africa Journal of Disability		
When was the work published?	Nov 27th 2020		
If the work was published prior to registration for your research degree, give a brief rationale for its inclusion	No		
Have you retained the copyright for the work?*	Yes	Was the work subject to academic peer review?	Yes

*If yes, please attach evidence of retention. If no, or if the work is being included in its published format, please attach evidence of permission from the copyright holder (publisher or other author) to include this work.

SECTION C – Prepared for publication, but not yet published

Where is the work intended to be published?	
Please list the paper's authors in the intended authorship order:	

Stage of publication	Choose an item.

SECTION D – Multi-authored work

For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)	Conceptualisation, design, led on investigation in the field and data analysis project administration, writing original draft and final editing

SECTION E

Student Signature	Maria Zuurmond
Date	08/12/2020

Supervisor Signature	Janet Seeley
Date	8th December 2020

African Journal of Disability
ISSN: (Online) 2226-7220, (Print) 2223-9170

Illuminating the empowerment journey of caregivers of children with disabilities: Understanding lessons learnt from Ghana

Authors:
Maria Zuurmond[1]
Janet Seeley[2]
Tom Shakespeare[1]
Gifty G. Nyante[3]
Sarah Bernays[4]

Affiliations:
[1]International Centre for Evidence in Disability, London School of Hygiene and Tropical Medicine, London, United Kingdom

[2]Department of Global Health and Development, London School of Hygiene and Tropical Medicine, London, United Kingdom

[3]Department of Physiotherapy, Faculty Biomedical and Health Sciences, University of Ghana, Accra, Ghana

[4]School of Public Health, Faculty Medicine and Health, University of Sydney, Sydney, Australia

Research Project Registration:
Project Number: ITCRZF56

Corresponding author:
Maria Zuurmond,
maria.zuurmond@lshtm.ac.uk

Dates:
Received: 04 Feb. 2020
Accepted: 23 Sept. 2020
Published: 27 Nov. 2020

Read online:
Scan this QR code with your smart phone or mobile device to read online.

Background: Empowerment is an increasingly popular goal, considered core to a transformative agenda for children with disabilities and their families. However, it can still be a poorly understood concept in practice.

Objective: This article is an empirical analysis of the 'empowerment journeys' of caregivers participating in a community-based training programme in Ghana.

Method: In-depth interviews were conducted with 18 caregivers at three time points over 14 months. Thematic analysis was conducted on the full data set, with three representative case studies selected for more detailed analysis to illustrate the dynamism of time and context in shaping the empowerment journey.

Results: Our findings illuminate the complexity and non-linearity of the caregiver empowerment journey. There were important gains in individual dimensions of power and the nascent emergence of collective power, through improved knowledge and valuable peer support from group membership. However, further gains were impeded by their limited influence over wider economic and sociopolitical structural issues that perpetuated their experiences of poverty, stigma and the gendered nature of caregiving. The support group facilitator often played a valuable brokering role to help traverse individual agency and structural issues.

Conclusion: A richer and more nuanced understanding of caregiver empowerment in the community and family context can inform the wider discourse on disability. Guidelines on working with people with disabilities, and the role of empowerment, should not neglect the pivotal role of caregivers. There are important lessons to be learnt if we want to improve family-centred interventions and transform the lives of children with disabilities.

Keywords: caregiver; carer; children with disabilities; empowerment; support groups.

Background

Whilst definitions of empowerment are diverse, it is generally agreed that it is a process, or outcome, that is multidimensional and seeks to shift prevailing power dynamics, which can be at the level of people, communities or organisations (Luttrell et al. 2007).

Empowerment as both a process and outcome for families of children with disabilities is seen as increasingly relevant. The pivotal role that families play in improving health outcomes for women, children and adolescents is outlined in the Global Strategy on Women's, Children's and Adolescents' Health (World Health Organization (WHO) 2016). This strategy calls for a transformative approach in which women and children can be the most 'powerful agents for improving their own health', through developing their own individual potential to make informed decisions, combined with active partnership with other stakeholders.

Empowerment is foundational to disability-inclusive development and community-based rehabilitation (CBR). It is one of the five pillars of the World Health Organization CBR matrix alongside the health, education, livelihood and social sectors. Empowerment is also a cross-cutting theme, and the guidance promotes the 'importance of empowering people with disabilities,

How to cite this article: Zuurmond, M., Seeley, J., Shakespeare, T., Nyante, G.G. & Bernays, S., 2020, 'Illuminating the empowerment journey of caregivers of children with disabilities: Understanding lessons learnt from Ghana', *African Journal of Disability* 9(0), a705. https://doi.org/10.4102/ajod.v9i0.705

Copyright: © 2020. The Authors. Licensee: AOSIS. This work is licensed under the Creative Commons Attribution License.

their family members and communities … to ensure that everybody is able to access their rights and entitlements' (WHO, UNESCO, ILO & IDDC). Empowerment is also a core element of the International Classification of Functioning, Disability and Health (ICF), a biopsychosocial model of disability, where disability is conceptualised as the product of an interaction between bodily function and personal and environmental factors. Personal factors include elements of individual empowerment, such as self-esteem and resilience, and equally an environment that facilitates empowerment is essential (Shakespeare & Watson 2001; World Health Organization & World Bank 2011).

Concepts and theories of empowerment and power

Much of the early conceptualisation of empowerment stems from the work of educationalist Paolo Freire; his work was essentially about the fight for social justice through social transformation, driven by power acquired through acquiring knowledge and resulting in the *conscientisation* of the individual, allowing them to drive change in their own lives (Freire 1996; Luttrell et al. 2007). These ideas were then heavily drawn upon in the discourse of how power could address poverty reduction in international development and establish that poorer people, through participatory empowering processes, are enabled to take more control over their lives (Chambers 1983, 1994).

Expanding on the work of Chambers, in the dialogue on gender and development, emphasis was given to the value of different dimensions of power, notably the personal and inner dimensions of power, as well as the need to examine the underlying structural drivers of oppression (Moser 1989; Rowlands 1997). Rowlands (1997) made a case for a more nuanced understanding of power, arguing that the earlier work on power (Foucault 1982) did not allow for factors that might influence an individual's agency to act, or the idea of collective agency, and that previous models did not shed enough light on the social mechanism of power. Instead, based on a gender analysis of power relationships, Rowlands proposed a three-dimensional empowerment framework, exploring power at the personal level, within close relationships and at a collective level. Power is then divided into four categories: (1) *power within*, which is about individual capability and self-worth; (2) *power to*, which is about the agency of the individual to take actions; (3) *power over*, which is about an individual's ability to access or influence economic, social or political factors; and (4) *power with*, which is about collective power to take actions with others (Luttrell et al. 2007; Rowlands 1997).

A parallel theory development was taking place in psychology in the 1980s on psychological empowerment (PE), focus on the individual and encompassing perceptions of personal control, a proactive approach to life and a critical understanding of the sociopolitical environment (Perkins & Zimmerman 1995; Zimmerman 1995; Zimmerman & Warschausky 1998). This model has three elements – intrapersonal, behavioural and organisational – with levels of empowerment varying across different life domains, for example, someone might be empowered in the home setting but not in the work setting, or vice versa.

At the same time, within the disability movement, the social model of disability placed an emphasis on removal of the structural barriers in society, in order to empower people with disabilities to overcome their experiences of oppression (Shakespeare 2006).

An additional important conceptualisation of power, found in Gaventa's power cube (Gaventa 2005), offers a different lens for understanding the complexities of power. He describes power as being on a continuum, with categories of visible, hidden and invisible power. 'Visible power' is described as observable decision-making dictated by formal rules and structures, 'hidden power' describes which people and institutions get to the decision-making table, whilst 'invisible power' is described as more 'insidious' and is the power that shapes the sense of self, influenced by social and cultural norms that can perpetuate what is considered normal and acceptable. The model describes how these forms of power must also be understood in terms of the spaces and places (from local to global) in which power might be exercised, coming together in a three-dimensional power cube. He argues that it is insufficient to just be in possession of power, but people must have the space to then exercise power.

A persistent debate that runs through all these theoretical discussions on power and empowerment relates to individual agency versus a structuralist approach to change. The structuralist perspective proposes that empowerment approaches should be primarily aimed at dismantling social, economic and institutional barriers to have greater influence over change, and the human agency perspective places a greater emphasis on individuals' capability to act rationally and autonomously (Baber 1991; Fazil et al. 2004). Instead, there is increasing recognition that both elements need to be present, are seen as complementary and dynamic forces (Luttrell et al. 2007) and are not binary; rather, there is a more fluid dynamic in how power operates. A review of the role of individual agency versus structural approaches in human immunodeficiency virus prevention concluded that this dichotomy was not helpful but that instead there needs to be a better understanding of the communities in which people act and connect in order to effect change (Kippax et al. 2013).

Operationalising empowerment

Since this theoretical development, 'empowerment' has become a ubiquitous term and an increasingly popular buzzword (Cornwall 2007). Some argue that as a result it is now a devalued term that has been hijacked and depoliticised from its original meaning (Batliwala 2015). Despite its common use in health programmes, there continues to be limited clarification of the meaning and

operation of 'empowerment' (Cornwall 2016; Crivello et al. 2014; Luttrell et al. 2007), and approaches focus too narrowly on individual change, such as adopting healthy lifestyles and improved self-efficacy of the individual (Laverack 2009).

Given the importance of empowerment in the CBR guidelines, it is also surprising that there is a dearth of literature on defining, understanding and measuring empowerment within programmes with people with disabilities in low-income settings (Rule 2013). Specific literature on caregiver empowerment is largely absent from the literature. In high-income settings, the lack of studies on what empowerment means in practice for family-focussed disability programmes has been highlighted, with a tendency for programmes to define and measure individual empowerment of the parent as an outcome of disability service provision (Banach et al. 2010; Nachshen 2005; Singh et al. 1995). In the United Kingdom, it has been argued that carer empowerment has received very little attention (Larkin & Milne 2014) and that too often the role of the mother is undervalued and peripheral in the discourse about children with disabilities (Ryan & Runswick Cole 2008). A study of an empowerment and advocacy programme in the United Kingdom with caregivers argued that insufficient attention is given to the social, cultural and familiar contexts and other structural issues that can limit the capacity to change (Fazil et al. 2004). Despite the popularity of the term, with some exceptions (Joseph 2020), it continues to not receive much critical attention.

Given this critique around the operationalisation of empowerment, and limited research on caregiver empowerment in the lives of children with disabilities in low- and middle-income settings, where arguably there is more dependency on families to provide most of the care, this article sought to examine the experience of empowerment of caregivers who engaged in a 1-year training programme in Ghana.

Methodology

Intervention

This article draws on data from a large pre- and post-intervention study to evaluate the impact of a caregiver training programme called Getting to Know Cerebral Palsy (LSHTM & Hambisela 2013). This was a 1-year programme, with 10 modules that were participatory in nature to promote critical thinking, problem-solving and peer support, based on principles of adult learning theory (Knowles 1984). The parent support groups were established by the local implementing partner, the Presbyterian Church of Ghana, in sites where they worked, and had an infrastructure for CBR or inclusive primary healthcare programmes. Up to 10 parents per area were invited to join a support group and participated in 3–4-hour training sessions on a monthly basis, with topics that included *understanding your child*, *communication*, *evaluating your child*, *play*, *eating*, *disability in your community*, *running your own parent group* and *everyday activities*. Referrals were also supported for assistive devices. Each caregiver had a child aged 18 months to 12 years with a confirmed diagnosis of cerebral palsy.

Caregivers also received a monthly home visit from a group facilitator and a community session to raise awareness about the programme. The groups were run by a pair of facilitators who were therapists, normally a local physiotherapist assistant combined with a primary healthcare worker such as a special needs teacher, nutritionist or a CBR worker.

The impact of the programme on well-being has been published (Zuurmond et al. 2018a, 2018b). In the broader study, 75 primary caregivers were invited to join a caregiver–parent support group in one of eight districts in Ghana. The primary caregiver was defined as the member of the family with the main responsibility for looking after the child. In this article, the research questions we seek to explore are: (1) to understand the role of empowerment of caregivers as they engaged with the training support programme and (2) to understand the key factors that shaped caregiver empowerment, at the level of the individual, family and community ecosystem.

Participant selection

Caregivers were identified through the community-based screening programme for cerebral palsy and through the hospital records of children diagnosed with cerebral palsy in the last 6 months. For the in-depth qualitative study, 18 families were then purposively selected from four sites, to ensure a geographical spread, different socio-economic status and a mix of children according to gender, age and severity of cerebral palsy. Eleven families were initially selected, and following the death of three children, a further five families were selected in the second round of interviews and two more at end line. Participant selection details are illustrated in Figure 1.

Data collection

A total of 37 in-depth interviews were conducted with 18 primary caregivers across three time points: 2 months before the start of the training programme; around 6 months into the training; and within 1 month of completion of the programme. Semi-structured interview guides were used, and all interviews were conducted in the home. The guides initially explored issues of what the child was able to do, what their understanding was of the condition, and who provided support within the family and questions about the caregiver well-being. Mid-term questions probed engagement with the programme and changes experienced. Topics also emerged through a process of iterative data collection and analysis in which areas of further investigation were developed in light of emerging ideas and concerns expressed in the interviews. Supplementary shorter interviews were conducted with selected secondary caregivers at the time of the household interviews, in order to capture additional perspectives on the caregiving experience within the

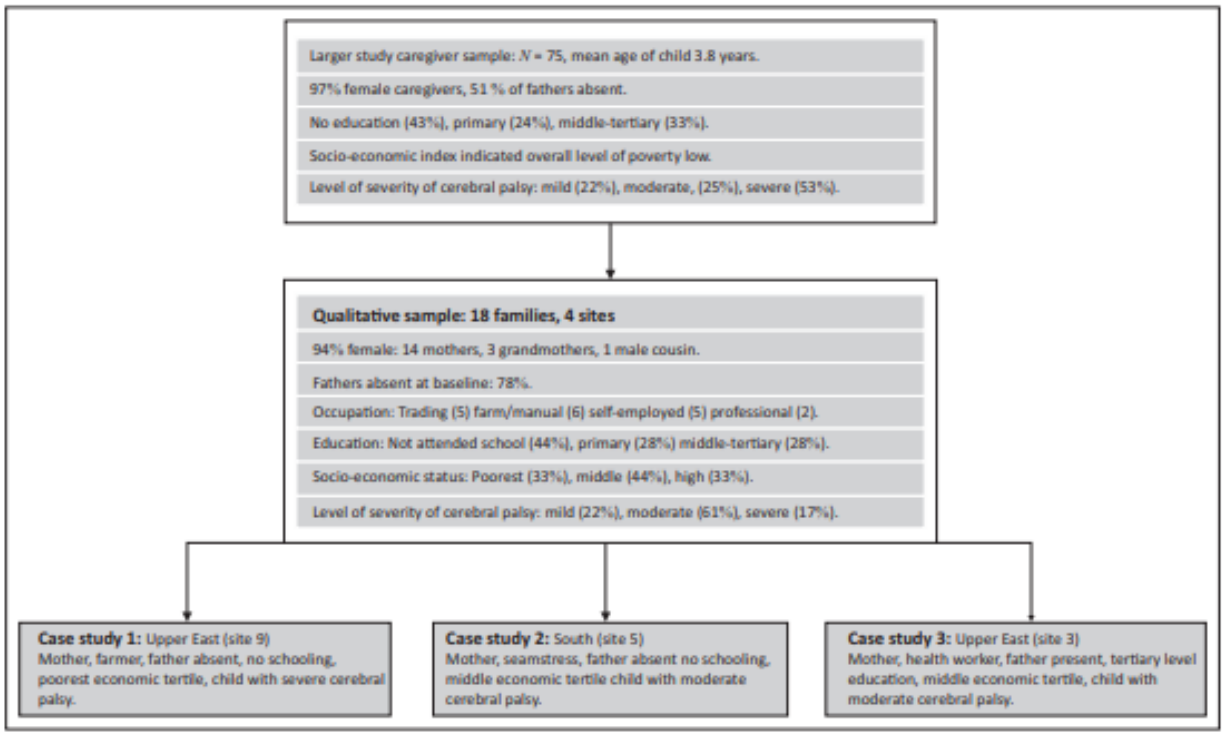


FIGURE 1: Details of sampling process.

household, and detailed field notes were kept. The interviews were conducted either by a local Ghanaian or by an international researcher (female Ghanaian, G.N.; white British female, M.Z.). Interviews were conducted in four local languages with translation into English as required. All interviews were audio recorded, translated into English and then transcribed.

Analysis

Two key stages of the analysis were conducted: a thematic analysis across all data from the 18 families at baseline, mid-term and end line and then a biographical case study analysis, which collated all the data from each family into a case study and detailed the change over time for each of the 18 families. The data included transcripts, as well as field notes and project monitoring forms, in order to provide a more holistic overview of their lives, in line with the guidance for longitudinal analysis (Creswell 2013; Green & Thorogood 2009).

For purposes of better illustrating the change over time, we are presenting three case studies. The case studies were selected to be representative of the larger sample (see Figure 1) and to illustrate and explore pertinent thematic concerns. Focussing on fewer individuals enabled us to obtain greater richness, detail and completeness than with other analytical approaches (Flyvbjerg 2013, Prior 2016) and helped us better illuminate the influence of the dynamic relational, social and economic context over time, which is not always captured so clearly by presenting a thematic analysis.

We used the conceptual framework of Rowland's model of power (Luttrell et al. 2007), as detailed in Table 1, to explore power across four different domains. We also applied the socio-ecological model (Bronfenbrenner 1994), which outlines the multiple ecosystems in which children and their caregivers are embedded, thereby exploring the domains of power at the individual, family and community levels.

Ethical consideration

Ethics approval was obtained from the Noguchi Memorial Institute for Medical Research, University of Ghana, and from the London School of Hygiene and Tropical Medicine (reference number: 8905; 25 March 2015), United Kingdom. Informed written consent was obtained from all participating caregivers, with a signature or thumbprint. All children identified with malnutrition were referred for follow-up, and the CBM child protection policy was adhered to. The case studies have all been provided with pseudonyms in this article.

Findings

Our case study families

Seventeen of the 18 participants were women: 14 mothers, 3 grandmothers and 1 male cousin. The overall level of caregiver education was low, with eight never having attended school and only three having attended high school or tertiary education. A socio-economic index illustrated that most families were extremely poor, and fathers were completely absent, lived separately or worked away from home, commonly with infrequent visits.

In summary, from the thematic analysis, the key emerging themes across the data from all 18 families were (1) acquisition of *power within* at the intrapersonal level, (2) the gradual development of *power with* other group members, (3) the brokering role of the group facilitator and (4) the economic and sociopolitical structural issues that very often limited the caregiver's *power over* change. The intersectionality of power with gender, poverty and stigma was also evident.

We organise our results by firstly presenting a case study and then linking the case study to the wider thematic analysis conducted on data from across all 18 families.

Case study 1: Jacinta and Maxwell

Jacinta, a single unmarried mother with two children, lived with her own mother in rural Upper East Ghana.

One of her sons, Maxwell, was 2.5 years old, had severe cerebral palsy and was severely underweight and stunted when we first met him. The grandmother had elephantiasis and had limited mobility. They were subsistence farmers, with some small additional income from hat weaving. The mother was unmarried, and the father of the children visited once over the 14-month period, bringing soap as a contribution to the household.

When we first met Jacinta, before she joined the support group, she did not raise her eyes from the ground. It was her mother who provided detail about how difficult their situation was, the particularly high levels of stigma experienced because of traditional views about the child and how isolated they felt. When we met Jacinta 6 months after attending the group, she laughed and chatted openly about the programme and talked of new skills acquired to improve the care for her son. She had felt confident enough to explain her son's condition to neighbours:

> 'Before, they [*neighbours*] used to insult me that I have given birth to a *Kinkiriku* [*spiritual child*]. They used to say this to the child: "Go away you, this Kinkiriku." That was before I knew the group. After I met the group, I always could explain to them what I learnt. Now they do that no more.' (Jacinta, code 9916)

Jacinta reflected on feeling valued as a 'human', having status conferred by the value of her group membership and meeting other mothers who shared the same situation, thus building her social capital, and also through feeling valued and worthy enough to be visited at home by a facilitator. Jacinta's case illustrated the development of the *power within* as she gained more self-confidence, self-esteem and feelings of self-worth:

> 'At first my mum and I used to weep. I thought I was the only one with this problem but when I saw my colleague women with similar problems, I realised that I wasn't the only one with this problem.
>
> I feel that we are also human beings and that is why people have come to visit us. Their coming makes me happy.' (Jacinta, code 9916)

In terms of *power to*, Jacinta was able to comment on her various improved caregiving skills, and she felt able to share that information with her biological mother, thus reducing her own caring workload. Despite these positive changes at the individual level, a lack of political and economic power remained a major impediment to Jacinta when we met her after 6 months. She had run out of cash for hat-weaving, and poverty was a major challenge, exacerbated by her inability to work away from home because of the need to look after her son. The family did not benefit from any social protection initiatives, such as the LEAP (Livelihood Empowerment Against Poverty) programme, because as they explained, they lacked political allegiance to community leaders: 'If you are not in their politics … you wouldn't be picked'. This demonstrated the invisible and hidden aspects of power that exist in communities and the lack of space made available to our caregivers to exercise their power. The group facilitator has good contacts with local community health workers, and he now facilitates Maxwell's inclusion in a nutritional programme, whilst Jacinta had previously been turned away.

This case study illustrates a prominent change across all caregivers, that is, improvement in their *power within*, over the 1 year. The solidarity of the support group was a common theme, frequently described as 'like a family', and the realisation that they were 'not alone' appeared to play an important role in their empowerment journey. Another common theme illustrated, and shared across most interviews, was a reduction in self-blame, generated from having more knowledge about their child's condition, thus helping with improved feelings of self-worth. Whilst Jacinta's case study illustrated the *power to* change her caregiving practices and share knowledge and skills with her own mother, the broader thematic analysis reflected mixed caregiver experiences. Frequently, relationships at the family level remained strained over the year, especially within the husband's family, and mothers continued to have little power within the social norms and power structures.

Case study 2: Beatrice and David

Beatrice was a confident and articulate young mother when we first met her. She had two children and lived on her own in the outskirts of Accra, renting one small room. Her son, David, was 4 years old and was diagnosed with severe cerebral palsy. Beatrice was a seamstress by trade, but because of full-time caregiving for her son, she was not working when we first met her, and this was a source of financial problems. Her husband left them shortly after her son's birth, blaming Beatrice for 'bringing disability into the family', and the last time he had visited was more than 3 years ago. He provided no support.

When we met Beatrice a second time at 6 months, there was growth of her *power within* and increasing evidence of *power to* take actions. She was positive about her newly gained knowledge, had implemented improvements in caring for her son and had taken steps to enrol David in school.

However, she was upset about how she had been treated by the head teacher, who turned her away and said the school was unsuitable for her son. The group facilitator was looking for another school. In terms of catalysts and impediments to empowerment, it was evident that the group facilitator played a vital role, using his own position as a special needs teacher and his networks to negotiate the 'hidden' and 'invisible' power of the education system, and being offered a space at the table to exercise that power. He finally secured a place for David at another school.

When we met Beatrice for the third time, after 14 months, the *power with* other group members to take collective action was slowly materialising. For example, several group members visited a mother who needed extra support in facing a difficult situation at home. In the absence of other community support mechanisms, the group 'family' appeared to be playing an increasingly valuable role as a social safety net for many of the caregivers. Sadly, Beatrice explained that she had 'regressed' since we last saw her, mainly because she had obtained a job as a seamstress, but then had lost the job and borrowed money to try a variety of small trades, all of which had been unsuccessful and resulted in debt. The most significant impediments to Beatrice's empowerment journey were her lack of economic power and her struggle to meet even the basic needs necessary for survival:

> 'There are days that I struggle to get something to eat and I sleep on an empty stomach. It is not just once. And I don't want to be a burden on the people I live in the house with … the little I have I give to the children.' (Beatrice, code 5558)

This case study illustrates the very common impact of poverty on caregivers' agency across the sample, with the exception of the only two mothers who were in regular paid employment. Poverty was exacerbated when a mother lived unsupported by the child's father or his family, as was the case for almost all parents in our sample. Even where mothers were living in extended families, a common theme was exclusion and a lack of power over economic resources within the household, which limited their power to take simple actions, such as buying more nutritious food for their child or taking their child for necessary health checks. As the local CBR manager reflected, for many of the families, 'empowerment starts with the stomach'.

The 'brokering' role of the facilitator in helping caregivers navigate their way was a recurring theme across all families, such as the facilitator helping to renew a health insurance card, to negotiate the administration of access to the Disability Common Fund, to help organise equipment repairs or to facilitate access to health or education services. Although the caregivers had acquired knowledge and confidence, social and political processes were still sometimes overly complex to navigate, or caregivers were not afforded a space to exercise their power. This was illustrated by one mother who finally had the confidence to go to the government office to register her daughter for the Disability Common Fund, only to be turned away.

Case study 3: Carol and James

Carol was educated to the secondary level and was one of only two mothers in the sample to have a professional job with a regular income; she was an administrator in the government health service. She was the only mother who had a husband living at home and who did not work away, and she had two daughters and a son. Her son, James, was a very bubbly smiling boy of 4 years old, with moderate cerebral palsy. Her son was turned away from the local government school because of his disability, but she chose a private school for him and drove him to school on her motorbike.

The first time we met her, before she started the programme, she described her fight to get a diagnosis for her son. After visiting various doctors over a 2-year period, she finally used her work network to approach the Regional Health Director to demand a diagnosis. This demonstrated high levels of self-confidence from the outset, actively seeking information and support. As the main breadwinner in the family, she had power over economic resources, and this facilitated her decision to send her son to private school and to obtain extra healthcare for him. Her case study mirrored the one other mother who was also in paid employment.

When we met Carol at 6 months, this *power within* had translated into her becoming a key mother within the support group, supporting the facilitator with running the group, and someone that other mothers turned to for support and advice. Although *power with* activities were still limited outside of the group, there were valuable examples of organising collective visits to each other's homes across all the groups:

> 'We are more like a family now; we share, we do everything together. When one is having problems, we look how to solve it, and when there is always a problem. I am always helping Fred [*the group facilitator*], and so we are always looking for a way to solve it.' (Carol, code 3340)

However, at 12 months, she tearfully explained that her husband was imprisoned, and she was struggling to hold down her full-time job whilst caring for all three children. She was also 6 months pregnant. Whilst she was happy that her son was making progress, and importantly was almost able to stand, she had recently come to realise that James had substantial visual impairment. This was a shock to her, that she was coming to terms with, and she was tearful and concerned that he might need to enrol in a school for the blind. She was looking for support and guidance from the group facilitator to help her navigate the educational and treatment choices for her son.

This case study illustrates the complexity of the empowerment journey, and mirrors the complexity of all the caregiver lives in this study, with the fluidity of changing support needs over time. In Carol's case, it was her husband's imprisonment, and the changing care needs of her son, that impacted on her empowerment journey. For other mothers, it was shocks such as being forced to leave rented accommodation because of

the stigma associated with their child's condition, a husband moving out to look for a second wife or the loss of work because of their caregiving duties.

Discussion

The article explores the journey of caregiver empowerment and the factors that shape this process for caregivers of children with disabilities. This offers a critique of the narrow understanding of what it means to 'empower a family' when the focus remains limited to the individual. Our analysis indicates the pertinent influence of broader relational and structural conditions in impeding the impact of an empowerment programme on the lives of caregivers and their children.

Instead, we offer a more nuanced understanding of that journey as caregivers engage with a community-based participatory training programme in Ghana. We found the metaphor of a journey useful, as proposed by Cornwall (2016), to describe the empowerment process. The pathway is wide; some terrain is easier with gains in some dimensions of power, whilst other paths are more difficult to traverse, and they may need more help. There are also a variety of routes, reflecting the non-linear nature of their journey, as caregivers respond to changes in their often-precarious lives, including the changing care and support needs for their child. Reynold's model of empowerment provides a useful framework for illuminating the different dimensions of caregiver empowerment.

In our study, it was evident that the individual *power within* was strengthened through the support group training. The value of this dimension of power should not be underestimated, given the profound levels of stigma and discrimination that are commonly experienced by caregivers, primarily mothers, for having a child with a disability (World Health Organization & World Bank 2011), and specifically the high levels of self-stigma and self-blame that are common to this group (Nyante et al. 2017). It may be that without developing power within, it will be difficult to achieve other aspects of power, but we also argue that the reduction of empowerment to individual agency alone is too limited.

The findings also illustrate, within the family ecosystem, that the *power to* take decisions and actions was facilitated or impeded by the hierarchy of kinship structures and the gendered nature of caregiving. This aligns with the need for greater understanding of the nature of human relationships in society and how that influences power (Green 2018). Additionally, within empowerment theory, there is a need to strengthen our understanding of how disability-related stigma plays out within the family context and interacts with power dynamics, within any model of empowerment.

In terms of *power over* economic and political resources, the linkages between poverty and disability are increasingly well documented (Banks & Polack 2014; Groce et al. 2011), but this literature is often focused on the adult with a disability, with less evidence of the impact of poverty on children and their caregivers. In Maslow's hierarchy of basic needs, he argues that physical survival needs must be met first before people can feel belonging and self-esteem and maximise their self-potential (McLeod 2007), and therefore operationalising empowerment for caregivers requires better understanding of the intersectionality with poverty.

We would argue that important changes occurred in caregiver feelings of self-worth and self-esteem that were essential stepping stones on their journey, but extreme poverty still limited their self-potential, when the main concern for some was putting food on the table. In the context of poverty, life is precarious for any family, but this research illustrates the augmented vulnerabilities brought about by having a child with a disability and how this shapes the possibilities for empowerment.

Therefore, drawing together these different experiences, our study shows that if we want to take a more transformative approach to maternal and child health for children with disabilities, it requires approaches that permeate the outer circles of the child and caregiver ecosystem. This is about a closer alignment with empowerment theory, which was always about looking at different dimensions and levels of empowerment and never only about the individual, even if that is more difficult for us to evaluate. There can be a tendency in the framing of family-focussed disability programmes, ours included, to lean more on the psychological framing of empowerment, about fostering change in the individual caregiver, but this study shows that it is about relationships, networks and structural issues.

Although not a focus of the initial programme, on completion of the study, the caregivers engaged collectively on a local advocacy activity through the local community radio to raise awareness about their issues. Other studies have similarly shown the power of collective agency for change by caregivers of children with disabilities (Elphick et al. 2015) and for improving community-level maternal health traditional practices (Badas et al. 2011; Morrison et al. 2010). This is an important element that could be strengthened within the future development of our programme. A study of self-help groups for caregivers of children with disabilities in Kenya also demonstrated that caregiver empowerment was associated not only with newly developed skills but also social connectedness and resource mobilisation (Bunning et al. 2020).

If we return to theories of empowerment, we would argue that it is also valuable to look at who can play a key role in the reorientation of power within the ecosystem layers. In our study, the group facilitator played a crucial role in brokering power over local social and political processes and thereby facilitating easier steps for caregiver empowerment. Local community health or education professionals are part of the

invisible and hidden power structures (Gaventa 2005) and thus are often better positioned to engage with these processes. There should not always be the expectation that caregivers, mainly women, can always be the prime agents of change, given that a range of factors coalesce around caregivers, including poverty, stigma, poor levels of education and gender, which may limit their ability, even collectively, to engage with social and political power processes.

At the same time, we also recognise the possible tension with creating dependency on a facilitator, and this is similarly explored in a critique of disability care in Africa (Morvan et al. 2014), or with CBR workers, who do not necessarily have the skills to foster empowerment (Rule 2013). This aligns with the argument made to enhance facilitator skills with a 'fifth power', the 'power to empower', as proposed by Robert Chambers (2012).

Finally, our study also calls for an improved understanding that the empowerment process is not always a linear one, especially when lives are so fragile. And given this fragility, and the long-term support needs for children with developmental disabilities, the empowerment journey is never likely to be a quick process; caregivers will have different support needs at different times. This is summed up in a discussion on women's empowerment: 'when we find the path we wish to tread, first walk in front of us; then, when we are stronger, walk beside us; and finally, when we are truly strong, walk behind us' (Batliwala 2015). We therefore need to be more realistic about operationalising theories of empowerment in practice for parenting programmes in low-resource settings.

Limitations of study

Future research would benefit from observations of the support group and of the home visit and understanding more about the role of the group facilitator. It would also benefit from revisiting the families after a longer time period in order to understand how some changes have evolved and are sustained. The families in the study were in areas supported by the local partner, the Presbyterian Church of Ghana, which typically works in areas of greater deprivation, and many of our families were the ultra-poor, where poverty was likely to play a greater role and where there were very low levels of caregiver education. Ultimately, this training is intended to improve outcomes for children with disabilities, and as such, children should also be taken on an empowerment journey. In this study, the majority of the children were under 5 years, but in any future study with older children the issues of children's empowerment should be explored.

Conclusion

New global maternal and child health strategies call for a more transformative approach, with women and children as agents of change. Empowerment is also core to the WHO CBR guidelines. Despite much work over the years on empowerment as a theoretical construct, research on how this works in practice for families of children with disabilities in low-resource settings is limited. We illustrate some important gains in caregiver empowerment as caregivers engaged with a participatory training programme in Ghana, in particular in terms of improvements in *power within* the individual. However, there are also multiple ways in which caregivers do not have access to decision-making; the gendered nature of caregiving, the intersection with poverty and disability-related stigma are key factors that limit their agency. We illustrate the lack of power over sociopolitical processes and the potential benefit of someone who can play a brokering role. There are limitations to any approach that places too much emphasis on individual agency and improved self-efficacy. A strengthened intervention needs to permeate the layers of the ecosystem in which the caregiver–child dyad is embedded, combined with addressing structural issues to foster a more enabling environment. There are important lessons to be learnt if we want to transform the lives of children with disabilities, and their families.

Acknowledgements

The authors thank Marjolein Baltussen and Jedidia Abanga for their support throughout the project. Thank you to Martine Collumbien for her discussion on empowerment early on in planning this article. The authors would also like to thank the members of the Ghana and international advisory board members, including Maxwell Akandem, Norgrove Penny, Eben Badoe, Mel Adams, David O'Banion, Sandra Carsamer, Melissa Gladstone and Cally Tann.

Competing interests

The authors have declared that no competing interests exist.

Authors' contributions

M.Z. was the project leader, responsible for the research design; she conducted the interviews and was the lead on analysis and writing of manuscript. J.S. and T.S. supervised the research and contributed to the editing of the manuscript. G.G.N. conducted the interviews, supported the analysis and contributed to the editing of the manuscript. S.B. supervised the research, contributed to the interview guides and overall design and edited the manuscript.

Funding information

Funding was provided by CBM International.

Data availability statement

Consent was provided by the families in 2015 for data to be shared within the research team only. This data sharing policy has now been changed at the London School of Hygiene and Tropical Medicine for all future projects.

Disclaimer

The views and opinions expressed in this article are those of the authors.

References

Baber, Z., 1991, 'Beyond the structure/agency dualism: An evaluation of Giddens' theory of structuration', *Sociological Inquiry* 61(2), 219–230. https://doi.org/10.1111/j.1475-682X.1991.tb00276.x

Badas, Ekjut, Women and Children First & UCL, 2011, *Community Mobilisation through women's groups to improve the health of mothers and babies*, viewed n.d., from https://www.womenandchildrenfirst.org.uk/

Banach, M., Ludice, J., Conway L. & Couse, L. J., 2010, 'Family support and empowerment: Post autism diagnosis support group for parents', *Social Work with Groups* 33(1), 69–83. https://doi.org/10.1080/01609510903437383

Banks, L.M. and Polack, S., 2014, *The economic costs of exclusion and gains of inclusion of people with disabilities*, CBM, International Centre for Evidence in Disability and London School of Hygiene & Tropical Medicine, London.

Batliwala, S., 2015, *Engaging with empowerment: An intellectual and experiential journey*, New Delhi, Women Unlimited, p. 299.

Bronfenbrenner, U., 1994, 'Ecological models of human development', *Readings on the Development of Children* 2(1), 37–43.

Bunning, K., Gona, J.K., Newton, C.R., Andrews, F., Blazey, C., Ruddock, H., et al., 2020, 'Empowering self-help groups for caregivers of children with disabilities in Kilifi, Kenya: Impacts and their underlying mechanisms', *PLoS One* 15(3), e0229851. https://doi.org/10.1371/journal.pone.0229851

Chambers, R., 1983, *Rural development-putting the last first*, Longman Scientific and Technical, Harlow.

Chambers, R., 1994, 'Paradigm shifts and the practice of participatory research and development', Institute of Development Studies: Working paper 2, viewed n.d., from https://opendocs.ids.ac.uk/opendocs/bitstream/handle/20.500.12413/3712/WP2.pdf?seq.%20IDS

Chambers, R., 2012, 'Robert Chambers on the Fifth Power (the power to empower)', viewed 02 February 2016, from https://oxfamblogs.org/fp2p/robert-chambers-on-the-fifth-power-the-power-to-empower/

Cornwall, A., 2007, 'Buzzwords and fuzzwords: Deconstructing development discourse', *Development in Practice* 17(4–5), 471–484. https://doi.org/10.1080/09614520701469302

Cornwall, A., 2016, 'Women's empowerment: What works?', *Journal of International Development* 28(3), 342–359.

Creswell, J.W., 2013, *Research design: Qualitative, quantitative, and mixed methods approaches*, London, SAGE.

Crivello, G., Vu, T.T.H. & Vennam, U., 2014, 'Gender, Agency, and Poverty: Children's Everyday Experiences in Andhra Pradesh and Vietnam', in M. Bourdillon, J. Boyden & R. Huijsmans (eds.), *Growing Up in Poverty: Findings from young lives*, Basingstoke, Palgrave Macmillon.

Elphick, J., De Saskropiwnicki, Z. & Elphick, R., 2015, '"Our children have the right to an education too": Strategies employed by orange farm caregivers of children with disabilities in pursuit of the right to a basic education', *Disability, CBR & Inclusive Development* 26(4), 101–116. https://doi.org/10.5463/dcid.v26i4.503

Fazil, Q., Wallace, L.M., Singh, G., Ali, Z. & Bywaters, P., 2004, 'Empowerment and advocacy: Reflections on action research with Bangladeshi and Pakistani families who have children with severe disabilities', *Health & Social Care in the Community* 12(5), 389–397. https://doi.org/10.1111/j.1365-2524.2004.00508.x

Flyvbjerg, B., 2013, 'Case study', in N.K. Denzin & Lincoln Y.S. (eds.), *Strategies of qualitative inquiry 4th edition*, London, Sage.

Foucault, M., 1982, 'Afterword: The subject and power' in H. Dreyfus and P. Rabinow (eds), *Michel foucault: Beyond structuralism and hermeneutics*, pp. 208–626, University of Chicago Press, Chicago.

Freire, P., 1996, *Pedagogy of the oppressed (revised)*, Continuum, New York, NY.

Gaventa, J., 2005, 'Reflections of the uses of the "power cube" approach for analyzing the spaces, places and dynamics of civil society participation and engagement', CFP Evaluation Series No 4, Falmer, England, Institute of development studies, viewed n.d., from https://www.participatorymethods.org/resource/reflections-uses-power-cube-approach-analysing-spaces-places-and-dynamics-civil-society

Green, D., 2018, *How Change Happens*, Oxford, Oxford University Press.

Green, J. & Thorogood, N., 2009, *Qualitative methods for health research*, London, SAGE.

Groce, N., Kett, M., Lang, R. & Trani, J.-F., 2011, 'Disability and poverty: The need for a more nuanced understanding of implications for development policy and practice', *Third World Quarterly* 32(8), 1493–1513. https://doi.org/10.1080/01436597.2011.604520

Joseph, R., 2020, 'The theory of empowerment: A critical analysis with the theory evaluation scale', *Journal of Human Behavior in the Social Environment* 30(2), 138–157. https://doi.org/10.1080/10911359.2019.1660294

Kippax, S., Stephenson, N., Parker, R.G. & Aggleton, P., 2013, 'Between individual agency and structure in HIV prevention: Understanding the middle ground of social practice', *American Journal of Public Health* 103(8), 1367–1375. https://doi.org/10.2105/AJPH.2013.301301

Knowles, M., 1984, 'The Adult Learning Theory - Andragogy', viewed 17 February 2015, from https://elearningindustry.com/the-adult-learning-theory-andragogy-of-malcolm-knowles

Larkin, M. & Milne, A., 2014, 'Carers and empowerment in the UK: A critical reflection', *Social Policy and Society* 13(1), 25. https://doi.org/10.1017/S1474746413000262

Laverack, G., 2009, *Public health: Power, empowerment and professional practice*, London, London Macmillan International Higher Education.

LSHTM & Hambisela, 2013, 'Getting to know cerebral palsy: Working with parent groups- a training resource for facilitators, parents, caregivers and persons with cerebral palsy', viewed 23 September 2016, from https://www.ubuntu-hub.org/resources/gtkcp/

Luttrell, C., Quiroz, S., Scrutton, C. & Bird, K., 2009, 'Understanding and operationalising empowerment', Working Paper 308. ODI, London.

McLeod, S., 2007, 'Maslow's hierarchy of needs', updated 20 March 2020, in *Simply Psychology*, viewed n.d., from https://www.simplypsychology.org/maslow.html

Morrison, J., Thapa, R., Hartley, S., Osrin, D., Manandhar, M., Tumbahangphe, K., et al., 2010, 'Understanding how women's groups improve maternal and newborn health in Makwanpur, Nepal: A qualitative study', *International Health* 2(1), 25–35. https://doi.org/10.1016/j.inhe.2009.11.004

Morvan, B., Magyarszeky, Z. & Holle, F., 2014, 'Perspective of the future of home-based care', in A. Vermeer and Z. Magyarszeky (eds.), *Disability care in Africa: Community-based rehabilitation in rural regions*, p. 347, Amsterdam, VU University press.

Moser, C., 1989, 'Community participation in urban projects in the third world', *Progress in Planning* 32 (Part 2), 71–133. https://doi.org/10.1016/0305-9006(89)90010-X

Nachshen, J.S., 2005, 'Empowerment and families: Building bridges between parents and professionals, theory and research', *Journal on Developmental Disabilities* 11(1), 67–76.

Nyante, G.G., Carpenter, C. & Igo, S., 2017, 'Conceptualization of cerebral palsy: Experiences of caregivers of children with cerebral palsy in Ghanaian rural communities', *Numid Horizon International Journal of Nursing and Midwifery* 1(1), 19–28. https://doi.org/10.7748/ncyp.28.7.19.s20

Perkins, D.D. & Zimmerman, M.A., 1995, 'Empowerment theory, research, and application', *American Journal of Community Psychology* 23(5), 569–579. https://doi.org/10.1007/BF02506982

Prior, L., 2016, 'In praise of small N, and of N= 1 in particular', *Critical Public Health* 26, 115–117.

Rowlands, J., 1997, *Questioning empowerment: Working with women in Honduras*, Oxford, Oxfam.

Rule, S., 2013, 'Training CBR personnel in South Africa to contribute to the empowerment of persons with disabilities', *Disability CBR & Inclusive Development*, viewed 11 August 2013, from http://dcidj.org/article/view/180

Ryan, S. & Runswick-Cole, K., 2008, 'Repositioning mothers: Mothers, disabled children and disability studies', *Disability & Society* 23(3), 199–210. https://doi.org/10.1080/09687590801953937

Shakespeare, T., 2006, 'The social model of disability', in L.J. Davis (ed.), *The Disability Studies Reader*, pp. 197–204, New York and London, Routledge.

Shakespeare, T. & Watson, N., 2001, The social model of disability: An outdated ideology?, in S.N. Barnatt & B.M. Altman (eds.), *Exploring theories and expanding methodologies: Where we are and where we need to go (Social Science and Disability)*. Bingley, United Kingdom, Emerald Group Publishing Limited.

Singh, N.N., Curtis, W.J., Ellis, C.R., Nicholson, M.W., Villani, T.M. & Wechsler, H.A., 1995, 'Psychometric analysis of the family empowerment scale', *Journal of Emotional and Behavioral Disorders* 3(2), 85–91. https://doi.org/10.1177/106342669500300203

World Health Organization (WHO), UNESCO, ILO & IDDC, 2010, *Community-based rehabilitation guidelines*, viewed 01 August 2013, from https://www.who.int/publications/i/item/9789241548052

World Health Organization, 2016, *Global strategy for women's, children's and adolescents' health, 2016–2030*, viewed 26 September 2017, from http://www.who.int/life-course/partners/global-strategy/global-strategy-2016-2030/en/

World Health Organization & World Bank, 2011, *World report on disability*, WHO, Geneva, viewed 19 December 2013, from http://www.who.int/disabilities/world_report/2011/en/index.html

Zimmerman, M.A., 1995, 'Psychological empowerment: Issues and illustrations', *American Journal of Community Psychology* 23(5), 581–599. https://doi.org/10.1007/BF02506983

Zimmerman, M.A. & Warschausky, S., 1998, 'Empowerment theory for rehabilitation research: Conceptual and methodological issues', *Rehabilitation Psychology* 43(1), 3. https://doi.org/10.1037/0090-5550.43.1.3

Zuurmond, M., Nyante, G., Baltussen, M., Seeley, J., Abanga, J., Shakespeare, T., et al., 2018a, 'A support programme for caregivers of children with disabilities in Ghana: Understanding the impact on the wellbeing of caregivers', *Child: Care, Health and Development* 45(1), 45–53. https://doi.org/10.1111/cch.12618

Zuurmond, M., O'banion, D., Gladstone, M., Carsamar, S., Kerac, M., Baltussen, M., et al., 2018b, 'Evaluating the impact of a community-based parent training programme for children with cerebral palsy in Ghana', *PLoS One* 13(9), e0202096. https://doi.org/10.1371/journal.pone.0202096

Chapter Nine Exploring caregiver experiences of stigma in Ghana - They insult me because of my child (Paper 4)

Photo 8 Mother and grandmother being interviewed at baseline line

In this chapter **(paper 4)** I explore the role of stigma in the lives of caregivers and how this shaped their engagement with, and impact of, the programme. This chapter addresses Study Objective 4, *'To explore the role of stigma in the lives of caregivers, and how it shapes engagement in the programme'*.

In the first section of the paper, I outline the concepts of stigma; from the pioneering work of Goffman in the 1960s, through to more recent conceptual frameworks of health-related stigma. I then review literature which highlights that families of people with health problems or impairments also warrant attention in understanding the diverse manifestation in which a stigmatised condition is experienced. This literature is limited when it comes to understanding the caregiver experience in SSA for children with disabilities. Through this paper I aim to better illuminate this experience, focusing on the personal and meso-levels.

The findings illustrate the pervasiveness of stigma related to disability in Ghana. Further, this paper demonstrates the often-detrimental consequences of social and internalised stigma experienced by the caregivers, who are predominantly mothers or other female caregivers.

The findings illustrate the intersectional nature of stigma. For example, the intersectionality of being a woman, and a mother/caregiver of a child with a disability, combined with other identities such as being extremely poor, and/or with low levels of education, and/or being a single mother. The social responses to particular aspects of cerebral palsy as a condition, such as drooling, are also shown.

Within the discussion I then reflect on some of the consequences of the impact of stigma; how poorer quality of life, including poorer mental health and feeling isolated, can in turn impact on caregiving. The implications for responsive caregiving in the early

years of a child's development are then discussed, arguing that this deserves greater attention.

The findings demonstrate how the programme appears to be valuable at addressing some dimensions of stigma, particularly at the individual internalised level. The support group operates 'like a family' at the meso-level to increase social support, and at the same time, reduces internalised feelings of self-blame and shame. However, I also explore the limitations in the reach of the programme within the different ecosystem layers, with family and community micro-systems often still remaining unfavourable environments.

LONDON SCHOOL of HYGIENE &TROPICAL MEDICINE

London School of Hygiene & Tropical Medicine
Keppel Street, London WC1E 7HT

T: +44 (0)20 7299 4646
F: +44 (0)20 7299 4656
www.lshtm.ac.uk

RESEARCH PAPER COVER SHEET

Please note that a cover sheet must be completed for each research paper included within a thesis.

SECTION A – Student Details

Student ID Number	461745	**Title**	Ms
First Name(s)	Maria Anne		
Surname/Family Name	Zuurmond		
Thesis Title	Understanding the lives of caregivers and evaluating a support programme for caregivers of children with disabilities: lessons learnt from Ghana		
Primary Supervisor	Janet Seeley		

If the Research Paper has previously been published please complete Section B, if not please move to Section C.

SECTION B – Paper already published

Where was the work published?	Disability and Society		
When was the work published?	01 Dec 2020		
If the work was published prior to registration for your research degree, give a brief rationale for its inclusion	No		
Have you retained the copyright for the work?*	Yes	Was the work subject to academic peer review?	Yes

*If yes, please attach evidence of retention. If no, or if the work is being included in its published format, please attach evidence of permission from the copyright holder (publisher or other author) to include this work.

SECTION C – Prepared for publication, but not yet published

Where is the work intended to be published?	
Please list the paper's authors in the intended authorship order:	

Stage of publication	Choose an item.

SECTION D – Multi-authored work

For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)	Conceptualisation, design, led on investigation in the field and data analysis project administration, writing original draft and final editing

SECTION E

Student Signature	Maria Zuurmond
Date	08/12/2020

Supervisor Signature	Janet Seeley
Date	8th December 2020

Disability & Society

ISSN: (Print) (Online) Journal homepage: https://www.tandfonline.com/loi/cdso20

Exploring caregiver experiences of stigma in Ghana: *They insult me because of my child*

Maria Zuurmond, Janet Seeley, Gifty Gyamah Nyant, Marjolein Baltussen, Jedidia Abanga, Sarah Polack, Sarah Bernays & Tom Shakespeare

To cite this article: Maria Zuurmond, Janet Seeley, Gifty Gyamah Nyant, Marjolein Baltussen, Jedidia Abanga, Sarah Polack, Sarah Bernays & Tom Shakespeare (2020): Exploring caregiver experiences of stigma in Ghana: *They insult me because of my child*, Disability & Society, DOI: 10.1080/09687599.2020.1851172

To link to this article: https://doi.org/10.1080/09687599.2020.1851172

Published online: 01 Dec 2020.

Submit your article to this journal

View related articles

View Crossmark data

Full Terms & Conditions of access and use can be found at
https://www.tandfonline.com/action/journalInformation?journalCode=cdso20

DISABILITY & SOCIETY
https://doi.org/10.1080/09687599.2020.1851172

Routledge
Taylor & Francis Group

Check for updates

Exploring caregiver experiences of stigma in Ghana: *They insult me because of my child*

Maria Zuurmond[a], Janet Seeley[b], Gifty Gyamah Nyant[c], Marjolein Baltussen[d], Jedidia Abanga[e], Sarah Polack[a], Sarah Bernays[b,f] and Tom Shakespeare

[a]London School of Hygiene and Tropical Medicine, Faculty of Infectious and Tropical Diseases, International Centre for Evidence in Disability, London, UK; [b]London School of Hygiene and Tropical Medicine, Faculty of Public Health and Policy, London, UK; [c]University of Ghana, Legon, Ghana; [d]CBM International, Bensheim, Germany; [e]Presbyterian Church of Ghana, Accra, Ghana; [f]The University of Sydney, School of public health, Sydney, Australia

ABSTRACT

Families of children with disabilities experience stigma by association with their child. This article examines social and internalised stigma experienced in the family by caregivers who participated in a caregiver programme in Ghana. Stigma is pervasive, and gendered, with most mothers blamed for bringing disability into the home. Emotional distress, isolation and lack of support are common experiences. We argue that the mothers can experience forms of disablism. Stigma is multi-layered, and a range of factors intersect with disability-related stigma, including poverty. A support group model can have a positive impact on caregiver internalised stigma and begin to address isolation. This should be part of a wider package of support to address wider structural issues. Families can play an important role in mediating change, but first we need to better understand the social disruption caused by disability-related stigma at the familial level.

ARTICLE HISTORY
Received 22 June 2020
Accepted 11 November 2020

KEYWORDS
Disability; child; caregiver; stigma; Ghana

Introduction

Stigma experienced by persons with disabilities is well-documented (Mostert 2016; World Health Organization and World Bank 2011). Less is known about the dynamics of stigma within the family of a child with a disability. This is despite the fact that families play a crucial care and support role, and arguably more so in low- and-middle income settings where services are scarce or non-existent (World Health Organization and World Bank 2011). In this article we explore the experiences of stigma among caregivers of children with

CONTACT Maria Zuurmond maria.zuurmond@lshtm.ac.uk London School of Hygiene and Tropical Medicine, Faculty of Infectious and Tropical Diseases, Keppel St, WC1E 7HT London, UK

© 2020 Informa UK Limited, trading as Taylor & Francis Group

cerebral palsy in Ghana who engaged with a caregiver training programme for children with cerebral palsy. First, we review the concept of stigma and the literature on stigma for caregivers of children with disabilities.

Concepts of stigma

Stigma is a complex social construct, and there have been various theories, categories and concepts. Goffman pioneered work on stigma in the 1960s, and defined stigma as as an 'attribute that is deeply discrediting' (3 1963) and reduces the bearer from 'a whole and usual person to a tainted, discounted one' *(*Goffman 1963*, 3)*. If the stigma is visible, then problems of interaction result, and the person is *'discredited'*. If hidden, then problems of information management result, and the person is '*discreditable'*. Although the work of Goffman can be helpful, the main criticism is that it focussed on the micro-level of the individual. Conflicting perspectives in the disability field put problems of interaction into the context of social barriers and social exclusion (Oliver 1990). Goffman's theory has now been further developed and reframed over the next fifty years to explain health-related stigma.

In extending the theory of stigma, Scambler (1989, 2009), in his 'hidden distress model of epilepsy', distinguishes between '*Felt*' stigma as distinct from '*Enacted*' stigma. Enacted stigma refers to overt examples of discrimination experienced. Felt stigma is the individual's internal feelings, such as a sense of shame, or anticipation about stigma, such as a fear of encountering possible discrimination. Increasingly, there has also been a greater focus on understanding the macro-level dimensions of stigma. Link and Phelan's model (2001, 2014) explores the effects of stigma and how they operate in relation to disability. Here the focus shifts from the effects of stigma on individual labelling, towards examining how an individual experiences oppression arising from wider society and environmental factors. Their model thus includes the broader operation of stigma in terms of institutional or structural discrimination *i.e.* having a 'disabling environment'. The notion of structural stigma resonates with Parker and Aggleton (2003) conceptual framework on AIDS-related stigma and the work of Corrigan, Kerr, and Knudsen (2005) on the stigma of mental illness where they argue for the need to examine structural discrimination which exists against certain groups at an institutional level, even in the absence of individual discrimination.

A further revised concept of health-related stigma outlined by Weiss, Ramakrishna, and Somma (2006) similarly portrays stigma as shaped by socio-cultural, historical, economic and political context, best understood through the social structures which moderate social interactions, emphasising the need to understand how stigma varies across different cultural contexts. This model usefully extends earlier concepts by distinguishing between

those who stigmatise and those who are stigmatised, and defines health-related stigma as '*a social process- experienced or anticipated - characterized by exclusion, rejection, blame or devaluation that results from experience, perception or reasonable anticipation of an adverse social judgement about a person or group identified with a particular pro*blem' (Weiss, Ramakrishna, and Somma 2006, 280)

Many of the later stigma concepts and models also emphasise the role of power, and that it takes power to stigmatise, but also that stigmatisation plays a role in producing and reproducing relations of power and control, intricately linked with social inequality (Link and Phelan 2014; Parker and Aggleton 2003). These models also emphasise the intersectionality of stigma with the health condition or impairment compounded by other factors such as poverty, gender and ethnicity (Link and Phelan 2001; Pescosolido and Martin 2015; Weiss, Ramakrishna, and Somma 2006).

A different but useful way of articulating the different levels of stigma is the notion of social, structural, and internalised stigma. Social stigma is enacted stigma or public stigma, operating at a meso level and is interpersonal in nature. Structural stigma or institutional stigma operates at the macro or systems level. Internalised stigma refers to the individual, and to self or felt stigma at the micro level, embedded within a sociocultural context. It is characterised by negative feelings about self, maladaptive behaviour, stereotype endorsement resulting from an individual's experience or anticipation of negative social reaction (Corrigan, Kerr, and Knudsen 2005; Livingston and Boyd 2010). It is this conceptualisation of stigma which we use in our study.

Stigma, the family, and caregivers

Attending to the interpersonal nature of social stigma, there is a growing recognition that the families of people with health problems or impairments warrant attention in understanding the diverse manifestation in which a stigmatised condition is experienced. Whilst the initial focus of the literature search was on families, this was extended into understanding how individual caregivers experience stigma. The term 'caregiver' is used to describe the main family caregiver, who is in an informal or unpaid care role (Shewchuk and Elliott 2000). This is predominantly a female relative, most notably mothers or grandmothers (McKenzie and McConkey 2016; World Health Organization and World Bank 2011).

Goffman first described stigma applied to people who associate with those who are stigmatised, such as family members, as 'courtesy stigma' (Goffman 1963). Later conceptual models also reflect the fact that people who do not have an impairment or illness, may themselves also experience

'felt' and 'enacted' stigma (Scambler 2009). Mak and Cheung (2008) coined the term 'affiliate stigma' to describe the internalisation of feelings which arise from being associated with a person with a stigmatising condition, leading to heightened emotions such as despair, anger or being behaviourally withdrawn.

Much of the literature on caregivers has focused on the broader experience of caregiving, with stigma as one component of the overall narrative. Literature which focuses on the role stigma plays in the family, particularly in countries in Africa, is more limited. Within this, the focus is often on caregiving for those with intellectual disability and mental health.

Internalised stigma

It has been argued by Yang, in a study of Chinese caregivers of people with intellectual disability, that internalised self-stigma is one of the most damaging forms of stigma for families (Yang 2015). In this study, internalised stigma is categorised into (1) feelings, such as shame, embarrassment and guilt, (2) cognition, with feelings of self-worthlessness and (3) behaviour, such as social withdrawal. Caregivers with concern about their social image, described as 'face stigma', were more likely to internalise feelings of shame, as did those in a lower socio-economic status group. Self-blame seemed to be particularly felt by those whose relatives were born with intellectual disability where the cause tended to be attributed to the family, such as the 'bad habits' of parents, or 'bad' genes. In the absence of clear diagnosis and aetiology, the resultant ambiguity around the cause also sometimes increased distress, although other studies offer mixed evidence about the links between attribution and stigma (Mak and Kwok 2010).

High levels of caregiver internalised stigma have been shown in studies across various country settings, with self-blame in part attributable to internalising others' accusations (Mak and Cheung 2008; Zhang et al. 2018; Huang, Kellett, and St John 2012; Johnson, O'Reilly, and Vostanis 2006). In one study, conducted in the US with families of children with autism, mothers who felt that their child was discriminated against by others in the community were more likely themselves to feel embarrassed, guilty, ashamed, resentful, and/or emotionally upset. One consequence of this was to self-exclude from social events (Gray 2002). Similar patterns were found in another US study where noted that, as their child was aging, mothers felt burdened with the fear that their child would be rejected, discriminated and isolated in the future (Green 2003).

In terms of studies conducted in Africa, there are few studies which have specifically looked at caregiver internalised stigma. However, within the limited empirical literature, similar patterns emerge. One recent study of children with developmental disabilities who attended a clinic setting in

Ethiopia, showed that 45.1% of caregivers reported feeling ashamed about their child's condition and 43.1% worried about being treated differently (Tilahun et al. 2016). The findings of this study did not show significant differences in levels of stigma across disability types, or age or gender of child.

There is some evidence that the experience of internalised stigma may vary depending on the types of disability. For example, a higher level of affiliate stigma has been shown among parents of children with autism in comparison to parenting a child with physical or intellectual disability (Werner and Shulman 2015), but other research has been equivocal on this (Tilahun et al. 2016).

Social stigma

Social or enacted stigma is more commonly captured in research on caregiving of children with disabilities. Those who stigmatise can be from the community, service providers, and within the family. This stigma is both directed towards the child, but also commonly towards family members and can reinforce caregiver feelings of self-blame and worthlessness (Huang, Kellett, and St John 2012; Johnson, O'Reilly, and Vostanis 2006).

Stigma within the family can manifest itself in terms of both physical and emotional conduct, and despite very different cultural contexts, similar issues emerge. These include family members not wanting to use the same furniture in the house as the child with the disability, not wanting to look at the child, and/or both caregivers and children experiencing negatives looks, negative language, being shouted at or insulted by both family and community members. Exclusion of caregivers with their child from family and community events is also commonly reported (Aldersey et al. 2018; Van der Mark and Verrest 2014; Qayyum, Lasi, and Rafique 2013; Heng-Hao 2009; Zuurmond et al. 2015; 2016; Patel et al. 2017).

Whilst studies reflect on social stigma within the family, fewer studies explore the gender dimensions, and how this may affect caregivers' experiences differently. A study conducted in Taiwan illustrated that mothers felt shamed and devalued by their husbands and parents-in-law because they had given birth to a child with cerebral palsy. Consequently, this discouraged them from feeling able to ask for help within the family (Huang, Kellett, and St John 2012). Bearing a disproportionate burden of caregiving while simultaneously being blamed by others within the family is a common experience of mothers and is noted within the literature across different settings. A study of Latina mothers of children with behavioural disorders demonstrates that they felt stigmatised because, within their culture, the primary responsibility for children's behaviour is assigned to the mother (Fernández and Arcia 2004). In one study in the United Arab Emirates, mothers reported being left by their husband, unable to

remarry, and 'blacklisted' by family and medical authorities for having a child with a disability (Crabtree 2007). Similar discriminatory and abusive behaviour of paternal relatives towards mothers, resulting in marital discord, abandonment of the mothers, and experience of domestic violence as a result of the blame placed on them has also been highlighted in a small number of other studies in Pakistan, Zimbabwe, the UK, and Tanzania (Qayyum, Lasi, and Rafique 2013; Van der Mark and Verrest 2014; Fazil et al. 2002; Aldersey 2012).

The resultant lack of support for caregivers is a recurring issue across both high and low income countries (Yang 2015; Ali et al. 2012; Johnson, O'Reilly, and Vostanis 2006). It can also be exacerbated by a common response whereby parents hide the child from the community and other family members, sometimes in fear of their child's safety, thus reinforcing social isolation. This isolation can also be further exacerbated by lack of availability of services (Roy McConkey, Kahonde, and McKenzie 2016; Heng-Hao 2009; van der Mark et al. 2019). As well as parents being fearful of violence, another consequence of social stigma is violence perpetrated by the parents themselves and by teachers, peers and community members (Njelesani et al. 2018).

In the context of Ghana, where our study is based, two ethnographic studies in the Upper East region have documented the phenomena of the '*Spirit child*' to refer to children with an 'abnormality' as '*bush spirits*' born into the family in human form (Denham et al. 2010; Awedoba and Denham 2014). These children are perceived to cause misfortune to the family, unless killed. Within this patrilineal system the mother is considered to be an 'outsider' within the family, and combined with her procreative power, it is interpreted that her 'behaviour' has put the family at risk (Awedoba and Denham 2014). Other studies in different regions of Ghana also document the abuse of children with disabilities as a consequence of stigmatising beliefs (Kassah, Kassah, and Agbota 2012), and how mothers of children with cerebral palsy experience substantial felt and enacted stigma which contributes to significant emotional maternal distress (Nyante 2016).

In this paper we explore the experience of stigma among caregivers with a child with cerebral palsy in Ghana, focussing on both the personal level and meso-level of the family.

Methodology

This paper draws on qualitative data from a larger study conducted in Ghana to evaluate the impact of a community-based caregiver training programme for children with cerebral palsy. Further details of this training programme, methodology, and impact on the quality of life of the child and caregiver have been published previously (Zuurmond et al. 2018; Zuurmond et al. 2019). Here we provide a brief summary.

Participant selection

Caregivers were identified through the community-based screening programme and hospital records of children diagnosed with cerebral palsy. Children were aged 18 months to 12 years, and caregivers had not attended any parent support group nor any regular physiotherapy with their child. Four (out of eight) sites were then purposively selected for a more in-depth qualitative study, ensuring a geographical spread, families of different, socioeconomic status, and a mix of children according to gender, age, and severity of cerebral palsy. A total of 18 families were visited up to three times over the course of the programme; two months before the start of the training support group programme; approximately six months into the training; and within 1 month of completion of the programme.

Description of programme

Community level support groups were established for 8–10 caregivers of children with cerebral palsy across each of the eight sites. The caregivers received a participatory training session of approximately half a day on a monthly basis, and one monthly home visit from a group facilitator over a 12-month period. The modular programme called 'Getting to know cerebral palsy' (LSHTM and Hambisela 2016) is further detailed in Additional document 1-**Insert** Diagram of training modules

Data collection and ethics

A total of 37 in-depth interviews were conducted. Seventeen of the 18 participants were women: 14 mothers, 3 grandmothers and 1 male cousin. The overall level of caregiver education was low, with eight never having attended school and only three having attended high school or tertiary education. A socioeconomic index illustrated that most families were extremely poor, and fathers were completely absent ($n = 11$) or lived separately/worked away from home commonly with infrequent visits ($n = 6$), as detailed in the paper on understanding impact on wellbeing (Zuurmond et al. 2019) .

Supplementary additional short interviews were conducted with selected secondary caregivers at the time of the household interviews, in order to capture additional perspectives on the caregiving experience within the household. Detailed field notes were also kept and incorporated into the analysis.

All interviews were conducted either by a local Ghanaian or an international researcher (female Ghanaian GN and White-British female MZ). Interviews were conducted in four local languages with translation into

English as required. Interviews were audio recorded, translated into English and transcribed.

Ethics approval was obtained from the Noguchi Memorial Institute for Medical Research, University of Ghana and from the London School of Hygiene and Tropical Medicine. Informed written consent was obtained from all participating caregivers, with a signature or thumbprint. All children identified with malnutrition were referred for follow-up, and the CBM child protection policy was adhered to.

Analysis

Two key stages of the analysis were conducted: a thematic analysis across all the interviews, and a biographical case study analysis. The data included transcripts, as well as fieldnotes, to provide a more holistic overview of caregiver lives in the local context, in line with guidance for qualitative analysis (Creswell 2013; Green and Thorogood 2009).

Findings

Social stigma at the familial level

Social stigma within the family was a strong recurring theme across almost every interview. This continued through the training programme, with some level of change. It included stigmatisers from extended family or community members, but there was also a high level of stigmatisation within the household. This presented in a variety of forms, towards the child, but also towards the primary caregiver. A common recurrent experience was rejection and attribution of blame to the mother by the husband and/or husband's family members for bringing a child with a disability into their family. As one mother reflected, '*they believe the sickness in the child is in my family*'. This manifested itself in different ways: family members not engaging with the child or helping with caregiving, as one caregiver described in tears '*they don't help me, I don't have anybody*'; the caregiver '*not on talking terms*' with other family members or with the community; and '*not taking care*' of the mother and child, even from family members living nearby.

In the two sites in the Upper East region, the patrilineal culture means that a wife typically lives with her husband's family and/or in the husband's village. In one case study, the mother lived with her husband's family whilst her husband worked away from home and visited once only over the study period of 14 months. The mother wanted to leave, and return to her own parents, because of a tense relationship with her mother-in-law who played a pivotal role in the family, at least around child-rearing practices:

> *My own mother in-law sometimes shouts at the child and I tell her that children like this should be treated with care and not to be shouted at. She leaves the child and begins to insult me. She doesn't help me. It's the children in the house here who help a lot in looking after her.* (Code 9990)

Exclusion enacted within the household appeared to be a particularly painful experience. This was illustrated by the case of another mother who described how her husband's family members avoided her, even when she played with her son in the communal courtyard. By the time of the final interview the father moved out of their shared room, and the family wanted her husband to divorce her, or look for a second wife.

One indicator of the high level of family-level stigma was the almost complete absence of fathers from the household, because of separation or divorce, working away from home for extended periods, or polygamy. Whilst in Ghana it is not uncommon for men to work away from home, the level was still high when compared to national data (Ghana Statistical Service 2015) and the fact that the child had a disability was often given as a reason for a husband leaving, living separately, or taking a second wife. There were, importantly, examples of where individual family members were supportive, and this was frequently from the maternal side of the family, such as sisters and maternal grandmothers, who offered a welcome safety net for the mothers and children.

Internalised stigma

In terms of internalised stigma, we found that caregivers' negative feelings about self and anticipated stigma were often interwoven in their narratives and it was not always possible to disentangle these different experiences. The internalised feelings about their child's condition were more evident in later interviews, accompanying the realisation that they were not to blame for the child's condition:

> *People used to say I have given birth to a Kinkiriku (spirit child). They said I have used him for money rituals. And that used to disturb me a lot… … … I used to be very sad each time they say this, but after I was told what was wrong with him, I worry no more* (code 9921)

The caregivers commonly reflected on the social stigma experienced in the community and family, which was then internalised into a variety of caregiver feelings, including anger, sadness, emotional distress, and '*feeling hurt*'.

> *Anytime I remember, I grow angry and even weep. He [my husband] came to tell me that in his family, no one has ever given birth to a child like this, so what I've given him is a curse. (Nav 02b)*

> *At first, when they insult me because of my child, I cry a lot (Code 3344)*

Caregivers described difficult relationships with the family, and it was sometimes difficult to disentangle what was exclusion and what was self-

exclusion. Feelings of blame over an extended period compounded by sadness, worry and stress, appeared to add to caregiver feelings of '*being on their own*'.

The case studies also illustrated the intersectionality of factors which shaped the caregiver's experience and served to magnify or mitigate the stigma experienced. This included levels of education, caregiver status in the community, and poverty. One mother, classified as extremely poor, worked as a day labourer, and had never attended school. She lived alone with her daughter who had severe cerebral palsy, together with an older son. She was a widower and explained that her husband's family were against the marriage, even before the birth of her daughter. She and her daughter were totally excluded within the community and '*no one will touch her* [daughter]', which meant that she carried her daughter even whilst working. In contrast, a nurse described how supportive her husband and his family were towards her and her son with cerebral palsy. Although her husband worked away from home, she lived in a hospital compound where her neighbours were from a medical background, '*were educated*', and frequently visited to give support. She also paid for a nanny to care for her son . She reflected on her experience of working in the local hospital, where children with disabilities were hidden and neglected as a result of her culture where '*many of our relatives and people in our community see these as children from a different place*' and consequently, '*if you are a mother then you are afraid to even bring this child out [of the house]*'.

Drivers of stigma

Traditional beliefs

Stigma was both driven and reinforced by pervasive traditional beliefs. In the Upper East region, across every interview, mothers referred to the term '*Kinkiriko*' (spirit child) which was commonly used to describe their child. This spirit could '*deceive*' the family. The researchers were shown a '*spirit hill*', where historically there was infanticide and whilst there is considerable work being done in the region to change this practice, it was evident that these beliefs still remained. Across other regions, traditional belief systems about disability and 'abnormality' similarly existed. For example, in Greater Accra, it was common to talk about their children having '*Asram*', a traditional illness of a new born which cannot be treated in hospital. One mother explained how in the past they would '*take the child to the river, shoot a gun, and the child would turn into a snake and return to the river*'. Despite different cultural explanations for the impairment across the different ethnic groups the reasons given still commonly reflected on the mother. For example, the she

may have been unfaithful, or some action that happened to the mother when she was pregnant, or using her child '*for money rituals*'.

One consequence of these beliefs was the use of different types of traditional healers, including taking a child to a church to '*cast out the spirit*'. 'Concoctions' of local roots and herbs from the traditional doctors sometimes caused convulsions in the child; if the child died and returned to the 'bush' this then confirmed her as a spirit child. These beliefs were exacerbated by low levels of knowledge about the condition and reinforced by the fact that there was often no diagnosis or cure for cerebral palsy at the hospitals, and rehabilitation services were scarce.

For example, M was five years old, had severe cerebral palsy and was severely malnourished when we first met her. Her mother had left her at the age of three years to be cared for by her grandparents in Upper East Ghana. It was a very poor household, and it was not uncommon for her to be left for hours lying on the ground whilst the grandmother went to the market. The grandmother explained that '*In our Frafra culture, once she [the child] cannot sit, they say it's a tree god that is responsible for that*'. She expressed fear about the power the child had over the family. The grandfather had recently organised a calabash of flour and two fowls for libation to treat the child when she was ill. Sadly, three months into the training, M died. Another mother from the same support group reflected on how the child was neglected because of the beliefs, and when attending the child's funeral the grandmother had continued to use negative words to describe the child, and '*acted like someone whose burden had now been lifted*'.

Social responses to the condition

The level of severity of cerebral palsy did not appear to play a role in the level of stigma experienced. However, there were some elements of the condition which further exacerbated the stigma, including, for example, if the child experienced epileptic seizures and/or drooling. It is not uncommon for some children with cerebral palsy to excessively drool, and this may trigger feelings of disgust, or possibly fear around contagion. One mother described having to separate from her husband and move out of their rented accommodation because the landlady would not go near the child even when '*the boy had moved to the edge of the veranda about to fall*', and was '*all the time complaining*'; the continual drooling was identified as a key reason for the landlady's attitude. Another mother described what was most useful from the training was understanding about the drooling, as ' *the child used to sit with her mouth full of saliva and they [community] used not to like associating with her*'. (Case 1194)

Contribution of the training programme

The data illuminated how the programme offered some support in addressing both social and internalised stigma. In particular the support group appeared to help in reducing feelings of self-blame and shame. These reductions in internalised stigma seemed a crucial element in building caregiver resilience, that is, their ability to cope and adapt even in the face of continued adversity within the family and community.

> *The change in my life is that sometimes I put my child on my back and went to my colleagues, and they made fun of me. I became angry and held a grudge against them. But now when I go to them and they mock me, I also laugh at them. So, this has brought about happiness and improved life for me.* (Code 3344)

The group support sessions offered a safe space to discuss their experiences and peer support, and this sometimes extended outside of the training. For example, one group of mothers visited another home where a child was regularly locked up: they wanted to give moral support to the mother because the husband wanted the child to be '*removed or even thrown away*'.

Yet, despite these positive changes, the caregiver narratives indicated that the environment of the family and community often remained unfavourable.

Discussion

This study showed the pervasiveness and often detrimental consequences of both social and internalised stigma experienced by caregivers in a family with a child with a disability in Ghana.

Our study demonstrates the intersectionality of gender and caregiving in framing the experiences of stigma, with blame largely attributable to the mother when there is a child born with cerebral palsy. These findings concur with the Link and Phelan's (2014) model of stigma that emphasises the centrality of power and illustrates the importance of attending to the gendered dimension of caregiving stigma. Our findings also concur with the argument made that mothers of children with disability can experience a form of disablism, and their role needs to be repositioned in the discussions on childhood disability (Ryan and Runswick-Cole 2008). In this way we argue they are likely to be in a better position to effect positive change for their children, alongside other family members.

In considering the intersectionality of caregiving our study highlights that we must attend to the role of relationships within the family, including the role of fathers. This is one of the few studies that has documented the absence of fathers in the household where there is a child with a disability (Zuurmond et al. 2018). Our findings illustrate the need for programmes which can effectively engage with fathers and address the challenges posed by absent fathers. Whilst fathers may not traditionally take on child-rearing

roles in many societies, their absence both reflects and reproduces stigma, which exacerbates the challenges faced by the female caregiver. She not only loses the support from him as an individual, but it also depletes her capacity to ask for help from others within the family. There are lessons that we can learn, for example, from more proactively engaging with fathers as part of an early intervention, and offering them some practical skills (Smythe et al. 2019). It is also important that any parenting programme is assessed through a gender lens and does not further add to the strain of caregiving.

Our findings are also in line with the few studies in Ghana that show how traditional beliefs related to disability are powerful and pervasive. This includes the view that children are not of human form, that the mother is blamed for bringing misfortune into the family as an outsider, and children with disabilities can be subject to various types of abuse (Denham et al. 2010; Awedoba and Denham 2014; Kassah, and Agbota 2012; Nyante 2016). This role of cultural beliefs fuelling stigma is well documented (World Health Organization and World Bank 2011; Riddell and Watson 2014), and where shame can be reinforced by traditional healers who attribute the disability to evil spirits or misdeeds (Roy McConkey, Kahonde, and McKenzie 2016).

In addition to gender, other factors which can layer on the disability-related stigma were also illustrated. Our findings draw attention to how household composition affects income and resources, so caregiving stigma intersects with the stigma that may come from extensive poverty or the consequence of being a divorced or separated mother. This ties in with the conceptual models which emphasise the intersectionality of various factors in the experience of disability-related stigma, such as caregiver education, standing in the community and poverty (Weiss, Ramakrishna, and Somma 2006; Link and Phelan 2006). Despite this, many programmes targeting the economic empowerment of persons with disabilities, are often not inclusive of caregivers and families (Stienstra and Lee 2019). We would argue that this is a missed opportunity to improve the lives of children with disabilities. Any parenting programme in LMIC settings which aims to address stigma should also consider economic empowerment of caregivers, combined with a package of caregiver supportive policies, as part of a multi-faceted approach.

Our research also illustrates that the complexity and heterogeneity of the condition 'cerebral palsy' is worthy of greater attention when understanding how this relates to social stigma. In our study, for example, drooling, which can be common with children with cerebral palsy, was particularly stigmatised, alongside epileptic seizures. Such negative responses to these physical symptoms, and the effect it has on social interactions, has been noted elsewhere (Fiest et al. 2014; Baskind and Birbeck 2005; Scior et al. 2013; Scior 2016). If we consider the ICF bio-pyscho-social model of disability (World Health Organisation 2007), then understanding the social responses to body

functions associated with the condition are important if stigma mitigation strategies are to be further strengthened. There is much we might also learn from research in areas such as epilepsy, where there is a large body of research on approaches to address stigma (Baskind and Birbeck 2005; Fiest et al. 2014).

In terms of the consequences of internalised or felt stigma, it has been argued that this type of stigma can be more disruptive than social or enacted stigma (Scambler 2009; Yang 2015). This study does not necessarily illustrate that one category of stigma is more disruptive than another, instead each category appears to mutually reinforce each other, exacerbating the caregivers' experiences.

One of the main consequences of stigma is the negative impact on mental health and quality of life, with wide-reaching consequence for the caregiver, their child and their household (Elafros et al. 2013; Zhang et al. 2018; Ali et al. 2012; Brouwers et al. 2011). The isolation experienced is likely to only exacerbate that, and arguably even more so when you feel the stigma of members of your own family. A quality mother-child dyad relationship, and responsive caregiving, are known to be critical in the early years for the child's development, (World Health Organization, UNICEF, and World Bank Group 2018), and arguably more so for children with a developmental disability who are likely to have additional needs (Kohli-Lynch, Tann, and Ellis 2019; Aboud and Yousafzai 2015) . It is well evidenced that maternal depression, and specifically postnatal depression, can result in adverse infant outcomes (Dadi, Miller, and Mwanri 2020; Herba et al. 2016). We argue, therefore, that far greater consideration needs to be given to the consequences of stigma on caregiving, specifically on maternal mental health, and in turn, on the implications for childhood development for children with disabilities.

Of course stigma is not the only factor contributing to caregiver stress and worry; other factors may include high level of multiple needs, challenges of feeding (Donkor et al. 2019; Polack et al. 2018) and inability to provide even basic needs because of poverty (van der Mark et al. 2019). However, our findings indicate that stigma is likely to further compound these challenges and efforts to address them need to simultaneously engage with ameliorating stigma to achieve sustained success.

Whilst this study illustrates the pervasive impact of stigma on the caregivers, our findings also indicate that the consequences can be reduced through engagement with a support group for caregivers. This model appeared to be particularly influential in reducing internalised stigma. At the meso level, the support group also augmented their social network of support and contributed to reduced feelings of isolation. This has the potential to be an essential intervention in addressing the paradox that ordinarily

caregivers are likely to have elevated care demands at the same time as they have diminished resources to draw on for support. Support groups provide an opportunity for caregivers to redevelop supportive structures and safety nets. We would argue that this is extremely important, given the paradox that the children are likely to have greater care needs, whilst stigma fuels a weakening of support structures and safety nets.

The ability of caregivers to challenge stigmatising attitudes within the family, as a result of training received, was less evident within our study. This highlights the potential limitations of an individual caregiver agency to influence the power dynamics of the household, and is explored in more detail in a separate publication on caregiver empowerment (Zuurmond et al. 2020). It also emphasises the need for a multi-faceted approach to stigma mitigation which engages with different levels and gatekeepers, as focusing on the individual caregiver alone will likely be inadequate.

Finally, whilst our findings highlight that family members can be perpetrators of stigma, it is vital to remember that family members can, and do, play a proactive role in tackling stigma, and promoting the rights of their children. The experience of stigma, although derived from a dense constellation of intersecting factors, is not fixed. It is malleable and families can be the powerful advocates for change. Our research and those of others indicate that families can play a crucial mediating role between the affected person and wider society (Roy McConkey, Kahonde, and McKenzie 2016; Elphick, De SasKropiwnicki, and Elphick 2016).

In terms of limitations, our study focus was on the lives of the primary caregivers, which was predominantly a female voice. Much of the available literature is similarly conducted with mothers and female caregivers as they were present in the household. The voices of fathers are largely absent, and we would need to try to include absent fathers in any future study. Furthermore, we did not directly interview children because of their young age, with an average age of 3.8 years. Future research is needed to explore both perspectives of fathers and of children and how they themselves experience stigma.

Conclusion

The narratives of caregivers emphasise the pervasiveness of traditional beliefs as a key driver of disability-related stigma in the Ghana context, for families with a child with cerebral palsy. Within the family, stigma is gendered. Female caregivers often carry most of the blame, seen as 'at fault' for bringing a child with a disability into the family, and experience both social and internalised stigma. Fathers, as well as other family members, need to be better engaged in the caregiving role.

Emotional distress, isolation and lack of support are common caregiver experiences, and we argue that the mothers can experience forms of disabling barriers. There is a consequential weakening of social support networks, thus compounding the strain of caregiving, with a negative impact on maternal mental health. The caregiver support group programme was found to help address internalised stigma and the isolation experienced, offering social support where it has been absent.

Understanding the social disruption caused by disability-related stigma at the family level requires greater attention if we are to improve the outcomes for children with disabilities, as well as their caregivers. Specifically, we need to better understand how mothers and the social fabric of the family experience the disability of their child in different cultural settings.

All of these experiences are not fixed or indelible, and the caregiving experience can be different and easier. Any programme targeting caregivers should addresses family level stigma, with a multi-faceted approach which can address the intersectionality of various factors, including poverty. This requires social protection measures and economic empowerment initiatives that are both disability-inclusive and caregiver supportive. A support group can be one valuable component to such a programme.

Acknowledgements

We would like to thank members of our Ghana team and advisory board members including Dr Norgrove Penny, Dr Eben Badoe, Dr Mel Adams, Maxwell Akandem, Dr Cally J. Tann, Sandra Carsamer, and Hannah Awadzi. Most importantly, we would like to thank all the participating families, especially the caregivers and children who participated in the programme.

Disclosure statement

There is no financial benefit or conflict of interest arising from this research.

Funding

This work was supported by the CBM International.

ORCID

Janet Seeley http://orcid.org/0000-0002-0583-5272
Sarah Bernays http://orcid.org/0000-0001-7628-8408
Tom Shakespeare http://orcid.org/0000-0003-2571-2787

Data availability statement

At the time of conducting this research, the ethics permission allowed for the data to be shared within the research team only.

References

Aboud, Frances E., and Aisha K. Yousafzai. 2015. "Global Health and Development in Early Childhood." *Annual Review of Psychology* 66: 433–457. doi:10.1146/annurev-psych-010814-015128.

Aldersey, Heather M. 2012. "Family Perceptions of Intellectual Disability: Understanding and Support in Dar Es Salaam." *African Journal of Disability* 1 (1)doi:10.4102/ajod.v1i1.32.

Aldersey, Heather M., Salome Kavira, Jeef Kiasimbua, Willy Lokako, Pelagie Miaka, and Lucie Monte. 2018. "Stigma Experienced by Families with Members with Intellectual Disabilities in Kinshasa, Democratic Republic of the Congo." *Intervention* 16 (2): 119. doi:10.4103/INTV.INTV_13_18.

Ali, Afia, Angela Hassiotis, Andre Strydom, and Michael King. 2012. "Self Stigma in People with Intellectual Disabilities and Courtesy Stigma in Family Carers: A Systematic Review." *Research in Developmental Disabilities* 33 (6): 2122–2140. doi:10.1016/j.ridd.2012.06.013.

Awedoba, Albert K., and Aaron R. Denham. 2014. "The Perception of Abnormality in Kasena and Nankani Infants: Clarifying Infanticide in Northern Ghana." *Ghana Studies* 15-16:41–68.

Baskind, Roy, and Gretchen L. Birbeck. 2005. "Epilepsy-Associated Stigma in Sub-Saharan Africa: The Social Landscape of a Disease." *Epilepsy & Behavior: E&B* 7 (1): 68–73. doi:10.1016/j.yebeh.2005.04.009.

Brouwers, Corline, Wim H. Van Brakel, Huib Cornielje, Paras Pokhrel, Krishna P. Dhakal, and Nandlal Banstola. 2011. "Quality of Life, Perceived Stigma, Activity and Participation of People with Leprosy-Related Disabilities in South-East Nepal." *Disability, CBR & Inclusive Development* 22 (1): 16–34. doi:10.5463/dcid.v22i1.15.

Corrigan, Patrick W., Amy Kerr, and Lissa Knudsen. 2005. "The Stigma of Mental Illness: Explanatory Models and Methods for Change." *Applied and Preventive Psychology* 11 (3): 179–190. doi:10.1016/j.appsy.2005.07.001.

Crabtree, Sara Ashencaen. 2007. "Family Responses to the Social Inclusion of Children with Developmental Disabilities in the United Arab Emirates." *Disability & Society* 22 (1): 49–62.

Creswell, John W. 2013. Research design: Qualitative, quantitative, and mixed methods approaches. 3rd Edition. London: SAGE.

Dadi, Abel Fekadu, Emma R. Miller, and Lillian Mwanri. 2020. "Postnatal Depression and Its Association with Adverse Infant Health Outcomes in Low-and Middle-Income Countries: A Systematic Review and Meta-Analysis." *BMC Pregnancy and Childbirth* 20 (1): 1–15. doi:10.1186/s12884-020-03092-7.

Denham, Aaron R., Philip B. Adongo, Nicole Freydberg, and Abraham Hodgson. 2010. "Chasing Spirits: Clarifying the Spirit Child Phenomenon and Infanticide in Northern Ghana." *Social Science & Medicine (1982)* 71 (3): 608–615. doi:10.1016/j.socscimed.2010.04.022.

Donkor, Claudia Mary, Jackie Lee, Natasha Lelijveld, Melanie Adams, Marjolein Meande Baltussen, Gifty Gyamah Nyante, Marko Kerac, Sarah Polack, and Maria Zuurmond.

2019. "Improving Nutritional Status of Children with Cerebral Palsy: A Qualitative Study of Caregiver Experiences and Community-based Training in Ghana ." *Food Science & Nutrition* 7 (1): 35–43. doi:10.1002/fsn3.788.

Elafros, Melissa A., Claire Sakubita-Simasiku, Masharip Atadzhanov, Alan Haworth, Elwyn Chomba, and Gretchen L. Birbeck. 2013. "Stigma and Psychiatric Morbidity among Mothers of Children with Epilepsy in Zambia." *International Health* 5 (4): 288–294. doi: 10.1093/inthealth/iht028.

Elphick, Jean, Zosa De SasKropiwnicki, and Rosalind Elphick. 2016. "Our Children Have the Right to an Education Too": Strategies Employed by Orange Farm Caregivers of Children with Disabilities in Pursuit of the Right to a Basic Education." *Disability, CBR & Inclusive Development* 26 (4): 101–116. doi:10.5463/dcid.v26i4.503.

Fazil, Qulsom, Paul Bywaters, Zoebia Ali, Louise Wallace, and Gurnam Singh. 2002. "Disadvantage and Discrimination Compounded: The Experience of Pakistani and Bangladeshi Parents of Disabled Children in the UK." *Disability & Society* 17 (3): 237–253. doi:10.1080/09687590220139838.

Fernández, María C., and Emily Arcia. 2004. "Disruptive Behaviors and Maternal Responsibility: A Complex Portrait of Stigma, Self-Blame, and Other Reactions." *Hispanic Journal of Behavioral Sciences* 26 (3): 356–372. doi:10.1177/0739986304267208.

Fiest, Kirsten M., Gretchen L. Birbeck, Ann Jacoby, and Nathalie Jette. 2014. "Stigma in Epilepsy." *Current Neurology and Neuroscience Reports* 14 (5): 444 doi:10.1007/s11910-014-0444-x.

Ghana Statistical Service. (2015, March). *Ghana Demographic and Health Survey 2014*. Accra: Ghana Statistical Service.

Goffman, Erving. 1963. *Stigma: Notes on the Management of Spoiled Identity*. New York: Simon and Schuster.

Gray, David E. 2002. "Everybody Just Freezes. Everybody is Just Embarrassed': Felt and Enacted Stigma among Parents of Children with High Functioning Autism." *Sociology of Health & Illness* 24 (6): 734–749. doi:10.1111/1467-9566.00316.

Green, Sara E. 2003. "What do you mean what's wrong with her?: Stigma and the lives of families of children with disabilities." *Social Science & Medicine* 57 (8): 1261–1374.

Green, Judith, and Nicki Thorogood. 2009. Qualitative methods for health research. 2nd Edition. London: SAGE.

Heng-Hao, Chang. 2009. "From Housewives to Activists: Lived Experiences of Mothers for Disability Rights in Taiwan." *Asian Journal of Women's Studies* 15 (3): 34–59. doi:10.1080/12259276.2009.11666072.

Herba, Catherine M., Vivette Glover, Paul G. Ramchandani, and Marta B. Rondon. 2016. "Maternal Depression and Mental Health in Early Childhood: An Examination of Underlying Mechanisms in low-income and middle-income countries ." Lancet Psychiatry 3 (10): 983–992. doi:10.1016/S2215-0366(16)30148-1.

Huang, Yu-Ping, Ursula Kellett, and Winsome St John. 2012. "Being Concerned: Caregiving for Taiwanese Mothers of a Child with Cerebral Palsy." *Journal of Clinical Nursing* 21 (1-2): 189–197. doi:10.1111/j.1365-2702.2011.03741.x.

Johnson, Robert F., Michelle O'Reilly, and Panos Vostanis. 2006. "Caring for Children with Learning Disabilities Who Present Problem Behaviours: A Maternal Perspective." *Journal of Child Health Care: For Professionals Working with Children in the Hospital and Community* 10 (3): 188–198. doi:10.1177/1367493506066480.

Kassah, Alexander Kwesi, Bente Lilljan Lind Kassah, and Tete Kobla Agbota. 2012. "Abuse of Disabled Children in Ghana." *Disability & Society* 27 (5): 689–701. doi:10.1080/09687599.2012.673079.

Kohli-Lynch, Maya, Cally J. Tann, and Matthew E. Ellis. 2019. "Early Intervention for Children at High Risk of Developmental Disability in Low-and Middle-Income Countries: A Narrative Review." *International Journal of Environmental Research and Public Health* 16 (22): 4449. doi:10.3390/ijerph16224449.

Link, Bruce G., and Jo C. Phelan. 2001. "Conceptualizing Stigma." *Annual Review of Sociology* 27 (1): 363–385. doi:10.1146/annurev.soc.27.1.363.

Link, Bruce G., and Jo C. Phelan. 2006. "Stigma and Its Public Health Implications." *The Lancet* 367 (9509): 528–529.

Link, Bruce G., and Jo Phelan. 2014. "Stigma Power." *Social Science & Medicine (1982)* 103: 24–32. doi:10.1016/j.socscimed.2013.07.035.

Livingston, James D., and Jennifer E. Boyd. 2010. "Correlates and Consequences of Internalized Stigma for People Living with Mental Illness: A Systematic Review and Meta-Analysis." *Social Science & Medicine (1982)* 71 (12): 2150–2161. doi:10.1016/j.socscimed.2010.09.030.

LSHTM and Hambisela. 2016. "Getting to Know Cerebral Palsy: Working with Parent Groups- A Training Resource for Facilitators, Parents, Caregivers and Persons with Cerebral Palsy." Accessed September 23, 2016. https://www.ubuntu-hub.org/resources/gtkcp/.

Mak, Winnie W. S., and Rebecca Y. M. Cheung. 2008. "Affiliate Stigma among Caregivers of People with Intellectual Disability or Mental Illness." *Journal of Applied Research in Intellectual Disabilities* 21 (6): 532–545. doi:10.1111/j.1468-3148.2008.00426.x.

Mak, Winnie W. S., and Yvonne T. Y. Kwok. 2010. "Internalization of Stigma for Parents of Children with Autism Spectrum Disorder in Hong Kong." *Social Science & Medicine (1982)* 70 (12): 2045–2051. doi:10.1016/j.socscimed.2010.02.023.

McKenzie, Judith, and Roy McConkey. 2016. "Caring for Adults with Intellectual Disability: The Perspectives of Family Carers in South Africa." *Journal of Applied Research in Intellectual Disabilities: JARID* 29 (6): 531–541. doi:10.1111/jar.12209.

Mostert, Mark P. 2016. "Stigma as Barrier to the Implementation of the Convention on the Rights of Persons with Disabilities in Africa." *Afr. Disability Rts. YB* 4:3. http://www.adry.up.ac.za/images/adry/volume4_2016/adry_2016_4_chapter1.pdf.

Njelesani, Janet, Goli Hashemi, Cathy Cameron, Deb Cameron, Danielle Richard, and Penny Parnes. 2018. "From the Day They Are Born: A Qualitative Study Exploring Violence against Children with Disabilities in West Africa." *BMC Public Health* 18 (1): 153 doi:10.1186/s12889-018-5057-x.

Nyante, Gifty Gyamah. 2016. "An Exploration of the Experiences and Perceptions of Primary Caregivers of Children with Cerebral Palsy Living in Rural Communities in Ghana." Coventry University. https://curve.coventry.ac.uk/open/file/8315e76f-aa7a-4532-9cec-c51033cc12a1/1/Gifty%20Gyamah%20Nyante%20PhD%20Thesis%20.pdf.

Oliver, M. 1990. *The Politics of Disablement*. Basingstoke: Macmillan.

Parker, Richard, and Peter Aggleton. 2003. "HIV/AIDS-Related Stigma and Discrimination: A Conceptual Framework and Implications for Action." *Social Science & Medicine* 57 (1): 13–24. doi:10.1016/S0277-9536(02)00304-0.

Patel, P.,. J. Baier, E. Baranov, E. Khurana, C. Gambrah-Sampaney, A. Johnson, B. Monokwane, and D. R. Bearden. 2017. "Health Beliefs regarding Pediatric Cerebral Palsy among Caregivers in Botswana: A Qualitative study." *Child: Care, Health and Development* 43 (6): 861–868. doi:10.1111/cch.12490.

Pescosolido, Bernice A., and Jack K. Martin. 2015. "The Stigma Complex." *Annual Review of Sociology* 41: 87–116. doi:10.1146/annurev-soc-071312-145702.

Polack, Sarah, Mel Adams, David O'banion, Marjolein Baltussen, Sandra Asante, Marko Kerac, Melissa Gladstone, and Maria Zuurmond. 2018. "Children with Cerebral Palsy in Ghana: Malnutrition, Feeding Challenges, and Caregiver Quality of Life." *Developmental Medicine & Child Neurology* 60 (9): 914–921. doi:10.1111/dmcn.13797.

Qayyum, Arisha, Seema Zainulabdin Lasi, and Ghazala Rafique. 2013. "Perceptions of Primary Caregivers of Children with Disabilities in Two Communities from Sindh and Balochistan, Pakistan." *Disability, CBR & Inclusive Development* 24 (1): 130–142. doi:10.5463/dcid.v24i1.193.

Riddell, Sheila, and Nick Watson. 2014. "Chapter 1: Disabilty, Culture and Identity: Introduction." In *Disability, Culture and Identity*, edited by Sheila Riddel and Nick Watson. London and New York: Routledge.

McConkey, Roy, Callista Kahonde, and Judy McKenzie. 2016. "Tackling Stigma in Developing Countries: The Key Role of Families." In *Intellectual Disability & Stigma: Stepping out from the Margins*. London: Palgrave-Macmillan.

Ryan, Sara, and Katherine Runswick-Cole. 2008. "Repositioning Mothers: Mothers, Disabled Children and Disability Studies." *Disability & Society* 23 (3): 199–210. doi:10.1080/09687590801953937.

Scambler, Graham. 1989. Epilepsy. London: Routledge.

Scambler, Graham. 2009. " Health-related stigma." *Sociology of Health & Illness* 31 (3): 441–455. doi:10.1111/j.1467-9566.2009.01161.x.

Scior, Katrina. 2016. "Towards Understanding Intellectual Disability Stigma: Introduction." In *Intellectual Disability and Stigma: Stepping out from the Margins*. London: Palgrave Macmillan.

Scior, Katrina, J. Addai-Davis, M. Kenyon, and J. C. Sheridan. 2013. "Stigma, Public Awareness about Intellectual Disability and Attitudes to Inclusion among Different Ethnic Groups." *Journal of Intellectual Disability Research*: JIDR 57 (11): 1014–1026.

Shewchuk, Richard, and Timothy R. Elliott. 2000. "Family Caregiving in Chronic Disease and Disability. 555.

Smythe, Tracey, Antony Duttine, Ana Carolina Dias Vieira, Barbara da Silveira Madeira de Castro, and Hannah Kuper. 2019. "Engagement of Fathers in Parent Group Interventions for Children with Congenital Zika Syndrome: A Qualitative Study." *International Journal of Environmental Research and Public Health* 16 (20): 3862. doi:10.3390/ijerph16203862.

Stienstra, Deborah, and Theresa Man Ling Lee. 2019. "Disabilities and Livelihoods: Rethinking a Conceptual Framework." *Societies* 9 (4): 67. doi:10.3390/soc9040067.

Tilahun, Dejene, Charlotte Hanlon, Abebaw Fekadu, Bethlehem Tekola, Yonas Baheretibeb, and Rosa A. Hoekstra. 2016. "Stigma, Explanatory Models and Unmet Needs of Caregivers of Children with Developmental Disorders in a Low-Income African Country: A Cross-Sectional Facility-Based Survey." *BMC Health Services Research* 16 (1): 152. doi:10.1186/s12913-016-1383-9.

van der Mark, Elise J., Ina Conradie, Christine W. M. Dedding, and Jacqueline E. W. Broerse. 2019. "We Create Our Own Small World': daily Realities of Mothers of Disabled Children in a South African Urban Settlement." *Disability & Society* 34 (1): 95–120.

van der Mark, Elise Jantine, and Hebe Verrest. 2014. "Fighting the Odds: Strategies of Female Caregivers of Disabled Children in Zimbabwe." *Disability & Society* 29 (9): 1412–1427.

Weiss, Mitchell G., Jayashree Ramakrishna, and Daryl Somma. 2006. "Health-Related Stigma: Rethinking Concepts and Interventions." *Psychology, Health & Medicine* 11 (3): 280.

Werner, S., and C. Shulman. 2015. "Does Type of Disability Make a Difference in Affiliate Stigma among Family Caregivers of Individuals with Autism, Intellectual Disability or Physical Disability?" *Journal of Intellectual Disability Research: JIDR* 59 (3): 272–283. doi: 10.1111/jir.12136.

World Health Organisation. International Classification of Functioning, Disability and Health: Children and Youth Version: ICF-CY. https://apps.who.int/iris/handle/10665/43737.

World Health Organization, UNICEF, and World Bank Group. Nurturing Care for Early Childhood Development: A Framework for Helping Children Survive and Thrive to Transform Health and Human Potential. https://apps.who.int/iris/bitstream/handle/10665/272603/9789241514064-eng.pdf.

World Health Organization and World Bank. 2011. *World Report on Disability*. Geneva: WHO.

Yang, Xue. 2015. "No Matter How I Think, It Already Hurts: Self-Stigmatized Feelings and Face Concern of Chinese Caregivers of People with Intellectual Disabilities." *Journal of Intellectual Disabilities* 19 (4): 367–380. doi:10.1177/1744629515577909.

Zhang, Yunjue, Mythily Subramaniam, Siau Pheng Lee, Edimansyah Abdin, Vathsala Sagayadevan, Anitha Jeyagurunathan, Sherilyn Chang, et al. 2018. "Affiliate Stigma and Its Association with Quality of Life among Caregivers of Relatives with Mental Illness in Singapore." *Psychiatry Research* 265: 55–61. doi:10.1016/j.psychres.2018.04.044.

Zuurmond, Maria, Ilias Mahmud, Sarah Polack, and Jenny Evans. 2015. "Understanding the Lives of Caregivers of Children with Cerebral Palsy in Rural Bangladesh: Use of Mixed Methods." *Disability, CBR & Inclusive Development* 26 (2): 5–21. doi:10.5463/dcid.v26i2.414.

Zuurmond, Maria, Gifty Nyante, Marjolein Baltussen, Janet Seeley, Jedidia Abanga, Tom Shakespeare, Martine Collumbien, and Sarah Bernays. 2019. "A Support Programme for Caregivers of Children with Disabilities in Ghana: Understanding the Impact on the Wellbeing of Caregivers." *Child: Care, Health and Development* 45 (1): 45–49. doi:10.1111/cch.12618.

Zuurmond, Maria, Velma Nyapera, Victoria Mwenda, James Kisia, Hilary Rono, and Jennifer Palmer. 2016. "Understanding How Carers Cope in a Complexchildhood Disability in Turkana, Kenya: Humanitarian Setting: Original Research." *African Journal of Disability* 5 (1): 1–8. doi:10.4102/ajod.v5i1.277.

Zuurmond, Maria, David O'Banion, Melissa Gladstone, Sandra Carsamar, Marko Kerac, Marjolein Baltussen, Cally J. Tann, Gifty Gyamah Nyante, and Sarah Polack. 2018. "Evaluating the Impact of a Community-Based Parent Training Programme for Children with Cerebral Palsy in Ghana." *PloS One* 13 (9): e0202096. doi:10.1371/journal.pone.0202096.

Zuurmond, Maria, Janet Seeley, Tom Shakespeare, Gifty Nyante, and Sarah Bernays. 2020. "Illuminating the Empowerment Journey of Caregivers of Children with Disabilities: Understanding Lessons Learnt from Ghana." *Africa Journal of Disability* 9 (0): a705. doi:10.4102/ajod.v9i0.705.

Chapter Ten Discussion, Recommendations and Conclusions

Photo 9 Grandmother discussing one of the parent handouts

In this chapter, I first summarise the main learning from each of the previous chapters, and review how they address each of the research objectives of the thesis. I then return to the proposed ToC for the caregiver programme, and review this in light of the collective findings from the study. This includes a brief exploration of the relationship between caregiver QoL, empowerment, and stigma. Next, in light of the findings of this research, I return to the ICF, and critique what this disability model provides in terms of understanding the lives of the caregivers, and their role for improving outcomes for children with disabilities. The

implications for future policy and programming are considered and a set of recommendations. Finally, I summarise the strengths and limitations of the study.

Background

Through the findings presented in this thesis, I have demonstrated the impact of a year-long training and support programme for caregivers of children with cerebral palsy and explored the lives of the caregivers as they engaged with the programme. The overall purpose is to inform and strengthen future approaches to engaging with these families in low-resource settings.

The rationale for the need for family-focused programmes is detailed in **Chapter one** and **Chapter two** of the thesis, and how the pivotal role of care and support at home is further accentuated by the scarcity of rehabilitation services in most LMICs (Rosenbaum, 2011, Yousafzai et al., 2014, Donald et al., 2014).

The specific objectives of the study were:

(1) To assess the impact of a caregiver training programme upon the lives of children with cerebral palsy and their caregivers in Ghana (addressed in **Chapter five, Chapter six**)

(2) To explore the pathways of change for caregivers participating in the programme, with a focus on understanding the impact on caregiver wellbeing (addressed in **Chapter seven**)

(3) To understand the role of caregiver empowerment within the programme pathway (addressed in **Chapter eight**)

(4) To explore the role of stigma in the lives of caregivers, and how this influences caregiver engagement in the programme (addressed in **Chapter nine**)

Reviewing the evidence: the lives of caregivers and the impact of parenting programmes

In terms of understanding the caregiving experience of families and thereby setting the scene for this thesis, I provide an overview of the literature on the caregiver experience for children with disabilities. I focus on the literature for caregivers of children with developmental disabilities in SSA, and the evidence available of the impact of parenting programmes. Whilst evidence highlights how many caregivers show love and care for their child, and develop various coping strategies, the resounding picture was of the strain of caregiving. Low levels of knowledge and understanding about the child's condition, exacerbated by the scarcity and poverty of services, are common across various countries and contexts. Many studies demonstrate the psychological impact of caregiving, with high levels of stress and anxiety, as well as the physical toll on the caregiver. Themes of isolation, lack of support, and stigma are recurrent. Poverty was identified as a key cross-cutting issue, with households further depleted by the additional costs of care, as well as the time needed for caregiving, with loss of time for income-generating activities. These multi-faceted challenges are influenced by, and in turn influence, factors at different levels of the child-caregiver ecosystem. One of the weaknesses identified in the studies was the lack of attention to the gendered nature of caregiving, and the implications of this for a model of care and support.

The evidence base for 'what works' for the caregiver training programme for children with developmental disabilities in SSA is detailed in this **chapter 2**, and highlights the dearth of

publications that evaluate both impact and process. It is this gap in the literature that this thesis sought to address.

The caregiver training programme, 'Getting to know cerebral palsy'

In **Chapter three** I outline the adaptation and earlier development of the caregiver training package*, GTKCP,* which is the programme evaluated in this thesis. I summarise the underpinning approach and theory, and the main content of the programme.

Methodology

The methodology employed in this thesis was detailed in **Chapter four**. This was a longitudinal study that employed qualitative and quantitative methods. The emphasis was on understanding the lived reality of caregivers from their perspective, and the design was thus rooted in an interpretive tradition. In summary, there were two components of data collection: (1) a questionnaire-based survey at baseline (prior to the training programme) and endline (up to two months after the training programme) with all children and caregivers enrolled in the programme; and (2) longitudinal qualitative research with families over a six to 15 month period (conducted both before they started the training and within two months of completion).

The ToC for the caregiver programme was detailed and drew upon various elements: 1) the caregiver literature, 2) earlier work by our team in Bangladesh (Zuurmond et al., 2015), 3) a participatory approach, combined with elements of adult learning theory which underpinned the training (Chambers, 1994a, Chambers, 1983, Knowles et al., 2005, Cox,

2015) 4), the ICF model of disability (World Health Organisation, 2007a) and 5) ecological systems theory (Bronfenbrenner, 1994b). I return to this in the section below on Revisiting the Theory of Change.

There were several key points of learning in relation to the methodology to reflect upon. The in-depth interviews with caregivers in the household afforded the opportunity to explore the lived experience of caregiving in detail, and probe more on impact of the training. This combined using unstructured observation at home, and discussions with the facilitators to tailor questions better to each family and enabled a more thorough exploration of change. The inclusion of a short interview with a secondary caregiver was also sometimes useful for providing a different perspective, for example on how learning materials were shared and adopted (or not) within the family.

For operational reasons (response burden concerns, age group of the children necessitating a proxy response and the need for more time to pilot and further refine) a measure of child participation was not included. Whilst the qualitative data afforded some information on child participation and wider inclusion in the family, it was limited. Information is therefore limited on this potentially important area of programme impact, and this should be addressed in future research. In future, it would be valuable to explore what participation means in the local context, and adapt and modify a child participation measure that is relevant to the local context.

Results

The results from the study are presented in **Chapters five** to **nine** of this thesis. The first study objective was to assess impact of the caregiver training programme upon the lives of children with cerebral palsy and their caregivers in Ghana. The second research objective was to explore pathways of change for caregivers in the programme, with a focus on understanding the impact on caregiver wellbeing.

In **Chapter five**, the impact of the training programme upon the child was shown to be mixed. There were improvements in some aspects of child feeding practices ($p<0.001$) and in the report on their child's physical and emotional health ($p<0.001$). However, malnutrition remained common at both time points; 63% and then 65% of children were classified as underweight, and 54% and then 64% classified as stunted, at baseline and endline respectively. There was a small but significant reduction in reported recent illness episodes (over the past two weeks) (64% to 50% $p<0.05$). However, frequency of reported serious illness over 12 months remained high (67%) among children.

The findings on malnutrition underline the need to prioritise early intervention to prevent and manage serious malnourishment, and to establish closer linkages between disability and malnutrition. These findings are in line with recommendations from other studies, which emphasize the importance of prioritising inclusive nutrition for children and adults with disabilities (Groce et al., 2013, Kerac et al., 2014). Related to serious malnourishment, this is also one of the few studies which report on the mortality ratio of children with developmental disabilities in a LMIC setting. The high mortality ratio highlights the extreme vulnerability of children of all ages, particularly for children aged 1±5 years who were almost

15 times more likely to die compared to children within the general population of the same age from a 'developing country[2]'(United Nations, 1982). Similar to a Bangladesh study, it was the children who were most severely malnourished who were then most likely to die (Khan et al., 1998). This requires further attention.

In terms of understanding the programme impact on the caregiver, there were a number of positive findings. Caregivers reported significant improvements in knowledge and confidence in caring for their child ($p<0.001$). A primary outcome was improved caregiver QoL, and this was assessed using both the *PedsQL™* family impact module and the LoL-QoL. The *PedsQL™* measure, with a clearly defined set of questions related to different domains of caregiving (Varni et al., 2004), was specifically developed to measure the impact of paediatric chronic health conditions on parents and the family. In contrast, the LoL-QoL is a generic measure and is not tailored specifically to caregiving (Camfield and Tafere, 2009, Cantril, 1965). The LoL-QoL offered a simpler measure, with emphasis on the caregiver deciding what was important to them, and the provision of explanatory information. In summary, the study showed extremely low caregiver scores at baseline, and a significant improvement in scores at endline, across both measures of QoL. This indicated that there were benefits to the training programme. There may of course have been the potential role of measurement bias and no control group was included for comparison. However, these findings aligned with the in-depth qualitative data, which is summarised below.

[2] The term 'developing country' is used as this is the term used in the UN model life tables that the data were drawn from.

Of particular value from using the LoL-QoL was the caregiver self-reported data captured, providing additional meaning to the scores. In particular, the LoL-QoL data highlighted the substantial financial pressures that impacted caregiver QoL. This remained a constant challenge in caregiver lives, despite the programme.

The findings presented in this thesis suggest that it is valuable to use both QoL measures, as they provide complementary data. The *PedsQL™* Family Impact Module is a tried and tested tool, internationally validated, tailored to the specifics of caregiving (Varni et al., 2004), and as a multi- item measure may be less prone to measurement error (Fayers and Machin, 2013, Gill, 1995). However, it does not capture the impact of other important contextual factors within the caregiver ecosystem, which may impact QoL. In this thesis, for example, the findings from the LoL-QoL indicated how addressing the poverty of the caregivers was considered fundamental to improving QoL.

The very young average age of the study children, and lack of suitable tools for younger children that have been adapted to LMICs, resulted in parent reporting as a proxy measure for child QoL. This is known to have limitations, already detailed in **Chapter six**. This should be explored in future studies to ensure that child outcomes, where possible, are not limited to parent measures of Qol, activity, functioning, and participation.

In **Chapter seven**, the in-depth longitudinal qualitative research provided data on the lived reality of caregivers as they engaged with the programme. The changes included:

improvements in caregiver understanding of their child's condition, reduced feelings of self-stigma, a shift towards a more positive and patient attitude towards their child, all of which were reflected in improvements in care and support. Increased hope for their child's future and greater caregiver resilience were noted, where resilience is defined as the ability to harness resources to sustain wellbeing (Southwick et al., 2014). The group membership appeared to offer a valuable social support network in the face of caregiver social exclusion; the value of such group membership has been recognised elsewhere (WHO 2011). The valuable role of the support group in improving wellbeing aligns understanding of the multi-dimensionality of the nature of QoL, and the importance of the context, including the importance of social relationships and understanding of the collective character of human wellbeing (Deneulin and McGregor, 2010, Ruta et al., 2007, Camfield and Skevington, 2008, WHOQOL group, 1995).

Illuminating the caregiver empowerment process

In **Chapter eight**, I explore the third research objective which sought to understand the role of caregiver empowerment within the programme. A summary of key concepts and theories on empowerment are detailed, and I recognise the multiple ways that the term 'empowerment' is employed. This study principally draws on an empowerment model from the gender and development movement, with categories of '*power within', 'power to',* '*power over'* and '*power with'* (Rowlands, 1997, Luttrell et al., 2009a).

Changes were largely evident, from the study findings, at the individual level, with caregiver 'power within' strengthened. This included positive changes in caregiver feelings of self-

worth and self-esteem. I argue that this change is particularly important given the profound levels of internalized self-stigma commonly experienced by caregivers, both in this study, and in other literature on caregivers with a child with a disability (World Health Organization and World Bank, 2011b, Nyante et al., 2017, Tilahun et al., 2016). In contrast, evidence of the 'power to' take decisions and actions was sometimes more limited. This was impacted by kinship structures and the gendered nature of caregiving, compounded by the interaction of other factors such as poverty, caregiver status in the community, and levels of social stigma experienced.

I conclude from the research that, within empowerment theory, there is a need to strengthen our understanding of how disability-related stigma plays out within the family context and interacts with power dynamics. Power over economic and political resources is another key issue that needs to be taken into account. Whilst there is much literature focused on the links between poverty and disability, it is most often focused on adults with disabilities (McLeod, 2007, Banks and Polack, 2014, Groce et al., 2011). I argue that the operationalization of caregiver empowerment thus demands a better understanding of the interaction of disability and caregiving, with gender and poverty, combined with factors such as caregivers' level of education, and position in the community, for example.

I also conclude from the longitudinal data collection that the empowerment journey is a non-linear one, as caregivers respond to changes in their often-precarious lives. Along this journey it is valuable to look at *who* can play a key role in the reorientation of power within the socio-ecological system layers. In this study, the group facilitators play a crucial

'brokering' role, as they are also often part of those invisible and hidden power structures in communities (Gaventa, 2005). Whilst there is arguably a fine balance between caregiver empowerment and creating dependency on using such facilitators (Lang and Stone, 1999), this brokering role can be beneficial when carefully developed, as similarly argued by Robert Chambers (2012).

Understanding the role of stigma

The fourth research objective addressed in **Chapter nine** was *'to explore the role of stigma in the lives of caregivers, and how that shapes their engagement in the programme'*. The study showed that disability-related stigma is powerful and pervasive in Ghana, fuelled by traditional beliefs. This is aligned with other research conducted in the Ghana context on beliefs related to disability, and in particular understanding of the 'spirit' child phenomena, which describes traditional beliefs that the child with a disability is not of human form (Denham et al., 2010, Awedoba and Denham, 2014, Kassah et al., 2012, Nyante, 2016, Denham, 2017). The findings showed that the support group model appeared to be particularly influential in reducing feelings of internalised personal-level stigma, whilst at the same time augmenting the caregiver social network of support.

This study added to current literature and theory in demonstrating the relationships between gender and caregiving in framing the experiences of stigma, with blame largely attributable to the mother when there is a child born with cerebral palsy. This underlines the importance of applying a gender lens to understanding the role of stigma within the family. I also showed how other factors layer on the disability-related stigma, such as

poverty, or the consequence of the status of the mother, such as being a single mother. This connects with conceptual models of stigma which emphasise such differences between people's positions and circumstances and the centrality of power in understanding how stigma manifests (Weiss et al., 2006, Link and Phelan, 2006, Parker and Aggleton, 2003, Link and Phelan, 2014).

Through the study findings, I also draw attention to the complexity and heterogeneity of the condition of cerebral palsy, and how bodily functions, such as drooling or epileptic seizures, are worthy of greater attention when understanding how this relates to social stigma. Negative social responses to such conditions as drooling have been similarly noted in other studies (Fiest et al., 2014, Baskind and Birbeck, 2005, Scior et al., 2013, Scior, 2016). This finding aligns with the ICF model of disability and illustrates the value of understanding how a particular condition might impact on bodily functions, which in turn interacts in a bi-directional way with activity, participation, and the environment.

Lessons learnt

In this section, I draw on the different chapters of the thesis, and reflect on what can be learned from a better understanding of the following:

1) The ToC underpinning the caregiver programme, with an exploration on learning from the study in terms of the relationship between caregiver empowerment, stigma and QoL.
2) The value of the ICF model of disability adopted in this thesis in providing a framework for understanding the role of the caregiver in childhood disability.
3) The implications of these findings for childhood disability policy.

Revisiting the Theory of Change

In this section I return to the original proposed ToC detailed in **Chapter four**, and review this in light of findings from the study. The ToC drew from the socio-ecological model of human development, whereby both the child and caregiver are understood to be embedded in, and interact with, different levels of the social system (Centers for Disease Control, 2015, Bronfenbrenner, 1994b). There was a particular emphasis in the programme on the microsystem and the role of the caregiver, within the family, support group, and their community. The socio-ecological model did provide a useful framing to understand the dynamics in these different layers. The findings from this thesis illustrate that any family-focused programme requires approaches that better address issues in the outer layers of the socio-ecological model, and how these permeate to the micro level of the family and caregiver-child dyad.

An example shown in this study is the Ghanaian social and cultural norms of the kinship structure in the macrosystem, and how the power dynamics linked to gender norms clearly impacted upon caregiving practice, and in turn impacted on aspects of caregiver agency. For example, that the power to take decisions and actions was impeded by the gendered nature of caregiving, and the relationship with issues such as disability-related stigma, and poverty.

Overall, the research found that economic factors linked to caregiving and disability require far greater attention in the programme design. A key assumption detailed in the ToC was that the caregiver has a '*certain basic level of economic empowerment.'* However, this assumption was not upheld in the Ghana context for this programme. Female caregivers

were frequently heading the household, often as a consequence of partner abandonment after having a child with a disability, and various issues compounded to exacerbate poverty levels, with caregivers commonly struggling to meet even the basic needs. The issue of poverty was also echoed in the findings detailed in **Chapter six**, where the caregiver LoL-QoL scores highlighted the caregiver's persistent concerns about livelihoods, and how that impacted on their assessed QoL. All of this resonates with the findings from the literature review in **Chapter two** that poverty is fundamental factor which shapes the caregiver experience.

Thus, any parenting programme needs to better address the issue of poverty and livelihoods, and the multiple interlinked challenges that specifically face poor women in caregiving roles. Related to this, there needs to be space to address wider organisational, policy, and legislative context for caregivers, as well as an environment which is enabling for women to access these policies. This is explored further below in the Section '*Raising the profile of caregiving'.* The need for parenting programmes to better address the wider nested system of environments, in which the caregiver is embedded, has been similarly argued in other studies about children with disabilities (Gladstone et al., 2017, Rosenbaum, 2011).

Again, the need to address all levels of the socio-ecological system, also relates to the issue of caregiver empowerment. In terms of the '*power within'*, the exploration of the pathways of empowerment in **Chapter eight** indicate the following key factors were identified as important for facilitating change: the acquisition of new caregiver skills, feeling valued and

having status conferred by the value of group membership, and having social support from this network. The latter included a realization for caregivers that they were not alone, and not to blame for having a child with a disability, as well as having a safe space for problem-solving together.

The findings from this study also reflect how empowerment is never only about the individual, yet there can be a tendency in the framing of family-focused disability programmes, GTKCP included, to lean more on the psychological framing of empowerment, and fostering change in the individual caregiver. It is often easier to address individual, rather than environmental or structural factors. The study emphasised the importance of needing to understand and address relationships and networks at the micro and macro level, as argued by others (Luttrell et al., 2009b, Batliwala, 2015, Rowlands, 1997).

The relationship between caregiver empowerment and the pervasive stigma towards disability in the Ghana context also emerges as a key issue that was not fully explored and considered in the ToC. Stigma is not limited to the child's experience, but is also an issue for caregivers, who, I argue, experience a form of disablism in **Chapter nine**. This in turn impacts on any model of home-based care and support. The findings show that stigma shapes, and is shaped by, factors at different layers of the socio-ecological model (Stangl et al., 2019), and gender and power is central to understanding the dynamics of stigma (Weiss and Ramakrishna, 2006, Link and Phelan, 2014). It is thus oversimplistic to propose that an 'empowered' female caregiver will effect changes in stigmatising beliefs within a complex

socio-ecological system, not least because of the gendered nature of caregiving, and the other multiple interlinking disadvantages they face.

In terms of the relationship between stigma and wellbeing, this research shows the negative consequences of stigma on caregiver wellbeing. Individual and social stigma experienced by the caregiver was shown to exacerbate isolation, and contribute to poorer caregiver QoL, again with consequences for their approach to nurturing care of their child. Only a few studies appear to have examined the link between stigma and QoL in caregivers (Elafros et al., 2013, Zhang et al., 2018, Ali et al., 2012, Brouwers et al., 2011). I argue that the links between disability-related stigma, caregiver QoL, and child development outcomes is an area which needs to be better understood.

The central role of social support and networks was another pillar of the ToC, and it was evident in this study that the parent groups do offer a valuable support network in an environment where many of the caregivers were otherwise isolated, exacerbated by scarce professional support. It was common in this study for caregivers to describe the group as '*like a family'.* This aligns with previous research which finds the development of social ties and support through self-help groups to be one of the key factors for driving change in other caregiver support groups (Bunning et al., 2020, De Sas Kropiwnicki et al., 2014) and that quality of interactions and relationships, especially family and community relationships, matter as much to wellbeing as do the quality of any material assets (Kippax et al., 2013, Camfield et al., 2009a). Other studies have also shown how a lack of social support can contribute to poorer caregiver health outcomes (Alaee et al., 2015, Al-Krenawi et al., 2011, Gupta et al., 2012).

Finally, the programme was underpinned by a participatory approach and aspects of adult learning theory to facilitate caregiver empowerment. Some elements of a support group model and the value of a participatory approach were reflected upon and detailed in **Chapters seven** and **eight**. Caregivers reported on the value of meeting others, talking through problems together, gaining skills through practice, and hope felt from seeing their own child develop, as well as the collective benefits from seeing other children improve. However, as detailed, there was less opportunity afforded through the programme for group collective action, which may have further contributed to impact. One limitation of my choice of methodology was that no data were collected at the level of the group, in terms of understanding how it functioned, and factors which may have contributed to the group being more or less successful. It was therefore difficult to evaluate the full extent to which participatory approaches and adult learning theory were adhered to in the delivery, and to interrogate the role that they played in the ToC. Fidelity to the training approach was only assessed subjectively by the project coordinator during one visit, and through monthly calls and feedback on the sessions on Whatsapp. This could be strengthened in a future study with a structured observation of the groups, clear indicators set to assess fidelity, combined with FGDs following group sessions, and interviews with the group facilitators.

Reviewing a model for childhood disability

In **Chapter one**, I provided a brief overview of some of the key theoretical models of disability, including the ICF which is the key model adopted in the study. I also briefly summarise some of main critiques of the ICF, notably that it still medicalises disability, does not sufficiently address broader structural issues that need to be politically addressed, with

too much emphasis placed on activity and participation levels (Pfeiffer, 2000, Mitra and Shakespeare, 2019, Barnes, 2012, Tøssebro, 2004). Here I return to the ICF-CYP model, in light of the findings from this thesis, and reflect on some additional limitations of this model in terms of understanding and guiding work on childhood disability.

Rosenbaum and Stuart (2004), and Yousafzai and colleagues (2014) suggest that the ICF model offers a useful framework for working with, and conducting research with, children with disabilities and their families. The importance of the child's environment is central, and thus places emphasis on the value of offering family-centred services. Rosenbaum (2012, 2011) then asks us to reconsider what are successful outcomes of programmes with children with developmental disabilities. Whilst most of this work is conducted in the high-income setting of Canada, he argues for greater emphasis to be placed on services which can improve outcomes for family wellbeing, even if this may be at the cost of the child's functioning. His argument is that the needs of families are integral to the wellbeing of the developing child and calls for research to explore, specifically, the connection between parent wellbeing and outcomes for children with disabilities.

However, whilst I concur that this study has demonstrated that the 'family' unit is a key environmental factor, and the importance of 'family' level outcomes, I argue that the ICF does not offer space to explain the pivotal role, particularly for early childhood development, of the *primary* caregiver, normally a mother or female family member. Arguably in Ghana and other LMICs, this role is even more accentuated, given the paucity of service provision and greater dependency on home-based care. The ICF-CY model would

benefit from being augmented by theory on early childhood development. In the latter, alongside specific characteristics of the child and in the context of caregiving, the '*psychological resources'* of any parent (Belsky, 1984p.83), are considered crucial for children to thrive (World Health Organization et al., 2018). Maternal depression, for example, has been shown to alter a mother-child interaction, and have an adverse impact on child health outcomes, and demonstrated as particularly prevalent in low-income settings (Dadi et al., 2020, Herba et al., 2016). Arguably the quality of the mother-infant relationship can be even more important for children with a developmental disability in LMIC settings, (Kohli-Lynch et al., 2019, Aboud and Yousafzai, 2015, Smythe et al., 2020b). Therefore, a better understanding of what influences caregiver wellbeing, including the pivotal role of caregiver-experienced stigma, and how that in turn impacts upon the caregiver-child dyad, would further enhance any model of child disability.

Interlinked with enhancing the model with a better understanding of the caregiver role, I also propose that the ICF model would benefit from a stronger gender lens. The ICF model appears to be 'gender blind' when it comes to understanding the nature of caregiving, and the relationship with other caregiver characteristics, such as socio-economic status and level of education, that in turn can fundamentally shape the caregiving experience within the family environment. As the literature review in **Chapter two** also highlighted, only a minority of studies which explore the caregiver experience reflect on the gendered nature of caregiving and any implications. Even more broadly in the disability literature in LMICs, when the intersection of gender and disability is discussed (Moodley and Graham, 2015, UN Women, December 2018) it is almost exclusively about the invisibility of women with

disabilities. It rarely touches on the broader issue of the gendered nature of caregiving, and the invisibility of the female caregiver. This may be understandable, as the role of family and unpaid caregivers is almost entirely absent from the UNCRPD, but I would argue that this is a gap that requires further attention, and more prominence in any model which looks at childhood disability.

In terms of other models of disability, I do not explore this in detail here, but it does seem that the central role of the caregiver is largely absent. Maria Berghs (Berghs, 2017), in her exploration of what the philosophy of Ubuntu has to offer for understanding childhood disability, argues that there is a need to move away from a socio-cultural explanation of, for example, the '*mother to blame'* for the disability, and shift the focus instead to promoting more collective responsibility and respect for diversity. Whilst building on indigenous knowledge, and the shift towards rights and responsibilities, and broader political engagement on disability rights is important, and also underpins the training approach in this study, I argue even the Ubuntu model would still benefit from encompassing a more nuanced understanding of the caregiver experience, particularly for women living in poverty in SSA. The multiple interlinking factors faced by these caregivers, with the gendered nature of caregiving at its core, need to be addressed if there is to be a more transformational approach to changing the lives of children with disabilities *and* their families. A similar argument has also been made recently in a study from South Africa which recognised the important agency of female caregivers in very difficult situations, but also highlighted how their isolation '*reinforces patriarchal standards of care and renders them largely invisible to policy makers and society'* (Van der Mark et al., 2019bp.8).

Implications of the research findings

In this thesis I have contributed to the body of evidence on the experiences of caregivers, particularly in SSA, and to understanding the impact and processes of a caregiver support programme. I have also contributed to the theoretical understanding of caregiver empowerment and stigma, and argued that the ICF-CYP could be further enhanced with a stronger attention to the role of the caregiver. In this section I explore some of the policy and programme implications of the research findings.

Whilst rigorous evidence is essential to inform any advocacy agenda, I am also driven emotionally by the many voices of mothers and grandmothers. The injustices that many of them have experienced in trying to look after their children, frequently in extremely difficult circumstances, is often not commanding attention. There appears to be a gap in the advocacy agenda for children with disabilities and their caregivers and families. I argue, for example, that when we talk about 'gender and disability', this should not just be about women with disabilities and their rights, however important, but it should also include an understanding of the gendered nature of caregiving. If not, I believe that we will fail to improve the lives of children with disabilities and miss essential opportunities for making a difference to early childhood development.

I argue for the need for better linkages to be made between disability studies and policy and programmes on early childhood development. In the latter, the 'psychological resources' of any parent are considered crucial for a healthy parent-child relationship (Belsky, 1984, Dadi et al., 2020, Herba et al., 2016), and critical in the early years for the child's development, as

detailed in the WHO nurturing framework for early childhood development (World Health Organization et al., 2018). The argument has been made that the quality of the mother-infant relationship can be even more important for children with a developmental disability in LMIC settings (Kohli-Lynch et al., 2019, Aboud and Yousafzai, 2015, Smythe et al., 2020b). Therefore, a better understanding of what influences caregiver wellbeing, and how that in turn impacts upon the outcomes of children with disabilities, is required.

Whose rights?

My own professional background over 30 years involves working with children and young people and employing a rights-based approach to ensure that the voices of young people with disability are heard. Therefore, initially, I was disappointed in this Ghana study that, with an average child age of only 3.8 years, I would not be able to engage directly with the children. However, one consequence of this was that the lives of the caregivers came more sharply into focus, and they were given more attention in the research design.

Returning to the first chapter of this thesis, I detailed the UNCRC (United Nations, 1989) and the UNCRPD (United Nations, 2006) as key frameworks. I would now argue that it is beneficial to build in a wider rights-based framework to also address the rights of caregivers. So, whilst I embrace the importance of '*nothing about us without us'* for persons with disabilities, I believe that, reflecting on this thesis, without also considering the rights of caregivers there is a danger that outcomes for children will not improve. This concurs with the argument made that mothers of children with disability can also experience a form of disablism (Ryan and Runswick-Cole, 2008). I propose that the argument does not need to be

about child rights versus caregiver rights but accept that such friction can exist. Jenny Morris elaborated on this tension in the UK setting, where feminist theorists argued against a model of community care, saying this amounted to female caregivers at home, which only served to perpetuate the woman's role in the family and her continued economic dependency. In contrast, persons with disabilities have a right to community care (Morris, 1991). Morris argued for an alternative path, whereby feminists can push for greater understanding and support for women's roles as caregivers and support the rights of children and adults with disabilities. I concur with this latter argument, and that it should be about upholding the rights of both.

Raising the profile of caregiving

Through the material presented in this thesis, I demonstrate the need to raise the profile of caregivers of children with disabilities. To tackle this, their role needs to become more apparent in any model of childhood disability, and thus given more weight in policies and programmes on childhood disability.

Whilst there are some unique issues which may be faced by a caregiver of a child with a developmental disability such as cerebral palsy, as illustrated in this thesis, there is also likely to be much in common with other types of caregiving. Is there something we can learn from looking more broadly at the role of care within the family from other sectors? For example, the wealth of literature on caregivers of older people (Schatz and Seeley, 2015) and the caregiver and HIV literature. The caregiver and HIV literature is extensive and beyond the scope of this thesis to explore in any detail, but a study of HIV-affected

caregivers showed that they shared similar experiences to caregivers who lived in poverty, and caregivers who support family members with special needs (Kidman and Heymann, 2016). Common issues included: insufficient income to adequately feed and clothe their families, lack of safe and affordable childcare, and loss of income-generating work due to caregiving conflicts. Another study explored in detail the difficulties faced by female caregivers as they negotiated their lives, and in a similar vein to this thesis, it concluded that HIV interventions would be unsuccessful without consideration of the wider context of women's lives (Harrison et al., 2014).

I conclude that there could be benefits in joining voices on the issues of caregiving, and not limiting ourselves to the disability sector. This might offer a stronger advocacy platform for raising the profile of the role of care, and thereby promoting caregiver-supportive policies. The opportunity now exists within the new Sustainable Development Goals, where Target 5.4 on achieving gender equality, requires us to *'recognise and value unpaid care and domestic work through the provision of public services, infrastructure and social protection policies and the promotion of shared responsibility within the household and the family as nationally appropriate*' (United Nations, 2015). We must at the same time be cognisant of the additional possible tensions in the context of the Disability Rights Movement, and the need to ensure that care in the community is in the interest of both the children (and adults) with disabilities, as well as the caregivers, who are largely women (Morris, 1991).

This thesis has illustrated how broader multi-faceted social and structural issues need to be addressed for a transformational and sustainable change in the lives of these families.

There is therefore a strong argument for greater attention to be given to livelihoods and social protection policies and programmes that, as well as being disability-inclusive, are also sensitive to caregiver needs. For example, research and guidance on the inclusion of persons with disabilities in livelihoods programmes, commonly focus on access for persons (adults) with disabilities (Mactaggart et al., 2018, United Nations, 2012, Stienstra and Lee, 2019), but rarely comment on the inclusion of caregivers of children with disabilities. Yet, as we showed in this thesis, if caregivers cannot return to work, or the nature of their work no longer fits with their caregiving role, then how can this be addressed?

Disability advocates

Although not a focus of this study, once the programme was completed, the caregivers engaged collectively through the local community radio to raise awareness of their issues. Other studies have similarly shown the power of collective agency for change by caregivers of children with disabilities (Elphick et al., 2016) and for improving community level maternal health traditional practices (Badas et al., 2011, Morrison et al., 2010). The strengthening of local level advocacy is an important element which could be further strengthened in future parenting programmes.

However, the study also illustrated that there should not always be the expectation that the caregiver, predominantly female, can always be the prime agents of change, given the range of factors that coalesce around caregivers, including poverty, stigma, poor levels of education and gender, which may limit their ability, even collectively, to engage with social and political power processes. I argue there is scope to look at a greater role for other

members of the family, as well as community disability advocates who can play a key role in the reorientation of power, and addressing stigma, within the socio-ecological system layers.

Strengths and limitations of the study

There are a number of strengths and limitations to this study as detailed below.

Strengths

This is one of the first studies evaluating the impact of a community-based caregiver intervention for children with cerebral palsy in SSA. It was conducted across eight different sites in Ghana, both in rural and peri-urban settings, involving families of communities of different ethnic groups. The sampling frame drew on data from a range of sources and included families who were no longer accessing health and rehabilitation services. The quantitative components used standardised questionnaires and clinical assessment of all participating children, by a paediatrician and experienced physiotherapist. It is a study which combines qualitative and quantitative methods, and this allowed for a triangulation of findings, the ability to capture different perspectives, and an immensely rich data set.

There were a number of benefits of the longitudinal qualitative research design. With repeat in-depth interviews I observed generally greater openness or willingness to share sensitive experiences and personal feelings. This may have been in part due to the positive effect of the caregiver engagement in the programme, as well as trust in the research team, and increased understanding of the research component by the participants.

The inclusion of a short interview with a secondary caregiver was also sometimes useful for offering a different perspective, especially on sensitive issues such as stigma, thereby providing a more holistic view of the family context. I found, for example, especially during first interviews, that some primary caregivers were less forthcoming about their stigma-related experiences. Instead, it was sometimes a secondary caregiver, such as a husband or a grandmother, who provided more detail.

Limitations

In terms of limitations, the study focus was on the lives of the primary caregivers, which was predominantly a female voice. Much of the available literature is similarly conducted with mothers and female caregivers as they were present in the household. The voices of fathers are largely absent, as is the case more generally in the literature reviewed from SSA. We would need to try to include fathers, including fathers who are absent from the child's care, in any future study.

There was no long-term follow-up after the intervention had finished, for example after six months, or more. Future studies should explore longer-term impact of the training and sustainability of the support groups. Collective action by the groups, including public engagement activities, occurred after the data collection phase, and it would have been of value to capture and understand that contribution. We recommend doing so in future studies.

The intervention is highly dependent on the quality of the facilitators and their ability to establish rapport with the caregivers. Future evaluations of similar interventions would benefit from including more observations of the group activities, including focusing on the relationships between facilitators and caregivers.

In terms of the pre-post-test survey, the participant numbers for the survey were not large, but they were comparable to other studies conducted with children with cerebral palsy (Yousafzai et al., 2014, Gona et al., 2014). There were limitations to the choice of study design, in particular the lack of a control group, in terms of attributing change to the intervention. However, this programme is now being further adapted in Uganda, and an RCT is currently being undertaken to assess impact (Nampijja et al., 2019).

We did not include a control group of caregivers and children who did not receive the intervention against which to compare, because of ethical reasons which have been earlier elaborated. Further we cannot rule out the role of social desirability in the responses of caregivers in their rating of QoL, and ratings of child health, which may be over-estimated. We could not directly assess children's QoL due to the lack of suitable tools for younger children and without using parents to offer a proxy measure, which has known limitations.

The target families were identified in areas supported by the PCG, who typically work in areas of greater deprivation, and so there may have been a selection bias, with our sample more likely to be financially poorer than the general population. Through additional

sampling in the qualitative research, there was inclusion of some additional families who were not categorised in the lower socio-economic quartile, in order that there was more exploration of how poverty shaped or did not shape the caregiving experience.

Finally, there was some pre-testing and reviewing of the training material in the Ghana context, as detailed in the methodology chapter, and the material was designed to be participatory in nature and build on local experience. However, it is likely that the programme may have benefited from an additional period of pre-testing in the Ghana context to ensure feasibility and acceptability to the local context. It was recognised that from a programming perspective there was an inevitable tension from the programming partner, CBM International, who wanted to initiate the programme as promptly as possible, and as soon as children were identified, given the known benefits of early intervention.

Summary of recommendations

Policy level

- Promote an approach which, in addition to a focus on the child, also addresses the needs of caregivers. Social policies need to be both disability-inclusive and caregiver-supportive. For example, promotion of mental health services and social services that are more widely available to family members and which can address the psychosocial needs of caregivers.
- Conduct a policy analysis to review social policies available for caregivers and identify gaps to be addressed. This should specifically address the issue of livelihoods and the challenges of poverty experienced and compounded, when caring for a child

with a disability. The low levels of caregiver wellbeing also emphasise the need to address the wider structural issues which impact on caregiving.

Programme level

- Extend family training and support programmes for the wider community; local personnel and leaders, such as teachers, primary health care workers, and faith leaders. This recognises the need to reduce the dependency on the caregiver as the main agent of change.
- Apply a gendered lens to any parenting/caregiver programme for children with disabilities, so there is not an additional burden placed on already-overstretched female caregivers.
- Strengthen collective advocacy activities in the parent support group model and place more emphasis on the power of collective agency for change.
- Ensure that stigma reduction interventions also recognise the role that family can make, and how family members can be supported in that role; and at the same time recognising that this needs to be part of a multi-faceted approach.
- Address structural issues, in particular the economic impact of caregiving a child with a disability. Livelihoods, including social protection and economic empowerment, should be addressed, or at least signposted, in the parenting programme.
- Explore opportunities in future programmes for positive engagement and collaboration with traditional healers, as part of a wider community awareness programme on child disability and the rights of the child with a disability. This is in recognition of the plurality of beliefs on disability, and the common use of traditional healers detailed. The role of traditional practises is complex and multi-faceted; they

may offer valuable services, but this thesis has also illustrated some harmful traditional practices which have been employed. The practise of going to multiple healers also comes with a substantial cost to families that are often already impoverished.

- Develop and strengthen a programmatic element that addresses caregiver psycho-social/mental health needs.
- Prioritise early intervention to prevent and manage serious malnourishment, and to establish closer linkages between disability and malnutrition.
- Ensure childhood disability programmes are better aligned with the ICF and include multiple outcome measures for both the child and family.
- Explore the use of caregivers as facilitators or as co-facilitators in the training, which may go some way to further strengthening their role as agents of change.
- Explore a role for disability advocates , building on the advantages detailed about the valuable 'brokering' role of the group facilitator. This may be as co-facilitators for support groups, and/or in additional roles to help navigate some of the power imbalances which caregivers have to engage with, both within and across different levels of the socio-ecological system.
- Expand opportunities for meaningful engagement with fathers and other key family members as one element of applying a gender lens to the programme and contributing to reduced caregiver burden.

At research level

Conduct research to explore the connection between parent wellbeing and child development in children with disabilities, and how this can be improved.

- Explore suitable measures for assessment of child participation and QoL to enrich our understanding of the impact of the programme on this important area, and in line with the ICF model.
- Explore longer-term impact of the training and sustainability of the support groups.
- This is one of the few studies which has collected mortality data for children with cerebral palsy in LMICs. This data should be more routinely monitored for all children with disabilities, and disaggregated by type of impairment and severity, to identify particular groups that may be more vulnerable.
- The piloting of the Lol-QoL showed a significant change as a result of the programme. It is a recommendation in future research to look at the psychometric properties of the LoL-QoL tool.

Conclusion

Cerebral palsy is the most common developmental disability globally, and these children will often have complex care and support needs over their lifetime. This study has shown that a participatory training programme targeting caregivers in a support group setting offer some important improvements in reported child health outcomes, although malnutrition is an important area which requires further attention. There were important positive changes in caregiver knowledge, confidence in their role, improved self-esteem with a reduction in self-stigma, with an overall improvement in caregiver QoL and wellbeing.

The support group mechanism appears to help foster caregiver improved wellbeing and elements of caregiver empowerment through the acquisition of new skills, feeling valued by the group membership, and having a social support from this network. The latter included a realisation by caregivers that they were not alone, with a reduction in self-stigma, as well as having a safe space for problem-solving. Importantly, through sharing experiences with other caregivers, this appears to engender a sense of hope that their child's life can improve. This thesis illustrates that the caregiver empowerment journey is not always linear, especially when lives are fragile. It also shows the importance of not only focussing on the notion of individual agency, but that empowerment is also about relationships, networks, and the need to address wider structural issues.

A high level of stigma is shown to be commonly experienced within the family. This experience has a gendered dimension, with blame largely attributable to the mother. The evidence indicates that the mothers in this study in Ghana can experience a form of disablism, which both impacts upon themselves, but also has repercussions on care and support for their child. It is evident that the gendered caregiver role needs to be better understood, and more central, to any disability model for children and young people.

The findings in this thesis illustrate the multi-faceted and interacting and compounding factors that directly and indirectly affect the lives of the caregiver-child dyad, and that a better understanding of this context is needed in the implementation of parenting

programmes; specifically how gendered caregiving, disability, poverty, stigma and empowerment interconnect. In the context of poverty, life is precarious for any family, but the augmented vulnerabilities brought about by having a child with a disability are shown. Thus, a strengthened approach to addressing structural issues, including poverty reduction strategies are required.

Finally, there is an urgent need for an advocacy agenda which raises the profile of caregiving. This includes promoting livelihoods programmes, including social protection programmes and policies, which are caregiver-supportive. This is needed if we are to further improve outcomes and take a more transformative approach to improving the lives of children with disabilities and their families.

Appendices - part 1

Appendix 1: Search terms

Caregiver terms:

Carer, Car* - also covers caring, care-giver, caretaker, expert parent, maternal* or mother*, paternal* or father*,family or families, parent*, grandparent

Child Terms: Child* Infant*

Developmental Disability terms

disabled child* (plus expanded terms for this)

child* with disabilit*

developmental disabilit* or neurodevelopmental disability* or neurodevelopmental disorder or developmental disability* or developmental disorder or intellectual disabilit* or intellectual development disorder* or intellectual deficienc* or mental deficienc* or mental retard* or mental handicap* or learning disorder* or Autis* or cerebral palsy

Time period: 2000-current

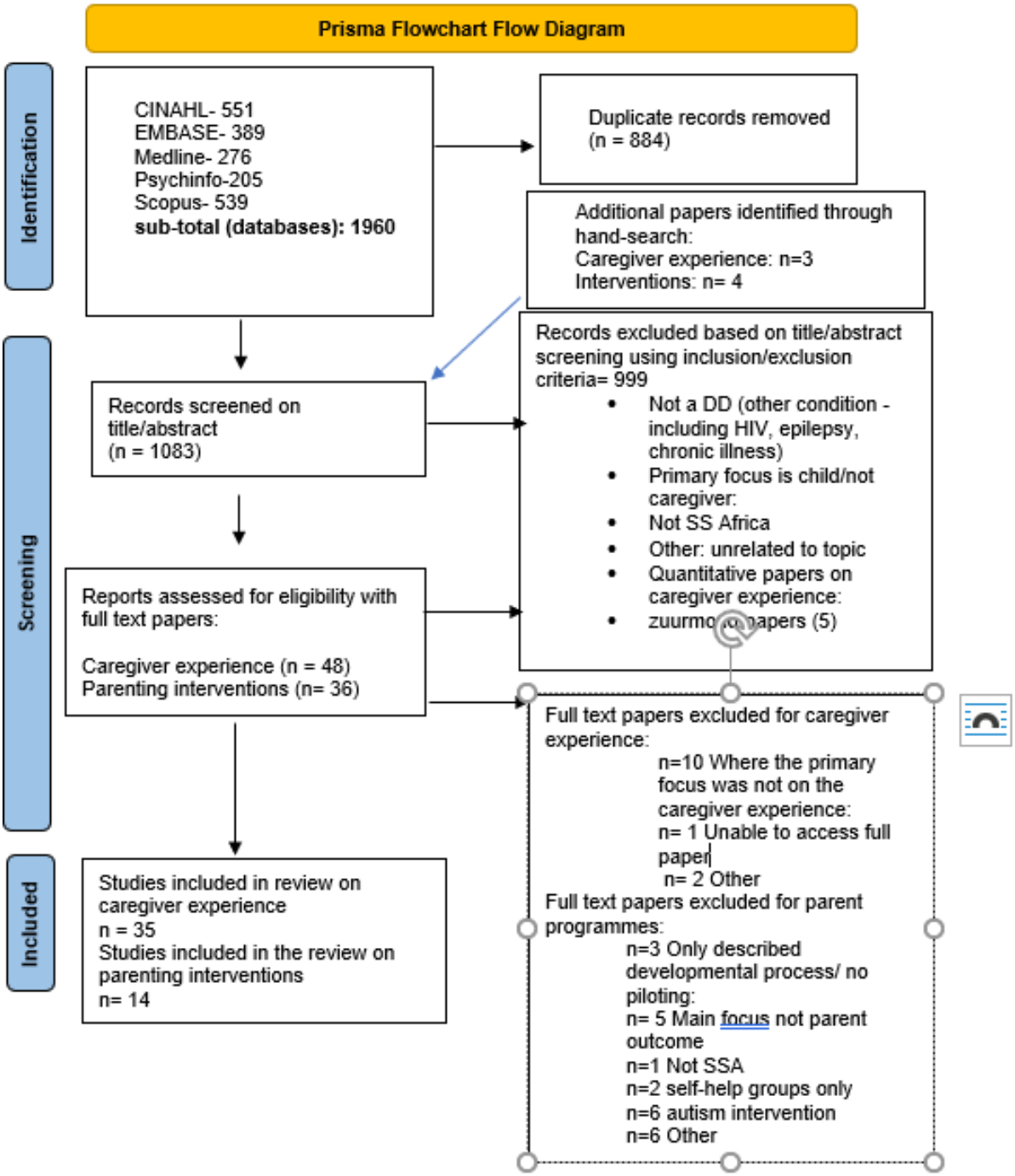
1. Caregivers/
2. (parent* or expert parent or caring).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
3. (maternal* or mother* or paternal* or father* or family or families).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
4. 1 or 2 or 3
5. (Central Africa or Eastern Africa or Southern Africa or sub-Saharan Africa or subsaharan Africa or Benin or Botswana or Burkina Faso or Cambodia or Cameroon or Kamerun or Cameroun or Cape Verde or Cabo Verde or Central African Republic or Ubangi-Shari or Chad or Congo-Kinshasa or Belgian Congo or Zaire or Congo Free State or Congo or Democratic Republic of Congo or Cote d'Ivoire or Cote divoire or Ivory Coast or Democratic Republic Congo or DR congo or Democratic Republic of Congo or DR of congo or Djibouti or French Somaliland or Dominica or Dominican or Eritrea or Eswatini or Swaziland or Ethiopia or Abyssinia or Equatorial Guinea or Ghana or Guinea or Guinea-Bissau or Portuguese Guinea or Kenya or East Africa Protectorate or Kiribati or Lesotho or Basutoland or Liberia or Malawi or Nyasaland or Mali or Marshall Islands or Mauritania or Mozambique or Mocambique or Niger or Nigeria or Rwanda or Ruanda or Sierra Leone or Somalia or Somaliland or South Africa or South Sudan or Sri Lanka or Sudan or Tanzania or Tanganyika or Zanzibar or Uganda or Zambia or Zimbabwe).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
6. limit 5 to yr="2000 -Current"
7. (child* adj4 (developmental disabilit* or neurodevelopmental disabilit or neurodevelopmental disorder or developmental disabilit* or developmental disorder* or intellectual disabilit* oror intellectual deficienc* or mental deficienc* or mental retard* or mental handicap* or learning disorder* or learning disabilit* or Autis* or cerebral palsy)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
8. (infant* adj4 (developmental disabilit* or neurodevelopmental disabilit or neurodevelopmental disorder or developmental disabilit* or developmental disorder* or intellectual disabilit* or intellectual deficienc* or mental deficienc* or mental retard* or mental handicap* or learning disorder* or learning disabilit* or Autis* or cerebral palsy)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
9. child development disorders, pervasive/ or developmental disabilities/ or intellectual disability/ or learning disabilities/
10. (child* or infant*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
11. 9 and 10
12. 7 or 8 or 11
13. 12 and 4 and 6

Figure 12: search strategy for Medline

(May2021). All terms for SSA.

Also tested various terms for parenting programmes, but found that they were identified through the broader search, so a separate search was not necessary:

Appendix 2: Flow chart detailing the review of papers from SSA



llowing general prisma guidance From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. RISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71
For more information, visit: http://www.prisma-statement.org/

Appendix 3: Papers included in the review of caregiver experience

Author	Date	Title	Country: Urban/ Rural	Study aim/s	Study design/ Summary methods
Aldersey, H. M.	2012	Family perceptions of intellectual disability: Understanding and support in Dar es Salaam	Tanzania: urban	*a) How do families conceptualise and experience disability? (b) What are families greatest support needs? and (c) What are the unique strengths of each family?*	IDIs N=13, purposive sampling from membership of local NGO (no data on gender of participants).
Aldersey, H. M., S. Kavira, J. Kiasimbua, W. Lokako, P. Miaka and L. Monte	2018	Stigma experienced by families with members with intellectual disabilities in Kinshasa, Democratic Republic of the Congo	DRC: urban	*To understand stigma experienced by family members of people with intellectual disabilities (IDs) in Kinshasa, DRC and (b) identify strategies used by these family members to mitigate or cope with stigma.*	Participatory. N=20 family (F=10, M=7 , + sibling/2 grandparents). Convenience sampled though network of one parent self-help organisations.
B. C. Chiluba; G. Moyo	2017	Caring for a cerebral palsy child: a caregiver's perspective at the University Teaching Hospital, Zambia	Zambia: urban	*To determine the experiences of parents/ caregivers of cerebral palsy children receiving out-patient physiotherapy*	IDIs (n=5) and caregiver strain Index/rehabilitation and Support Questionnaire survey to n=25 parents (F=92% M= 8%), purposive sample at outpatient hospital.
B. Tekola; M. Kinfe; F. Girma; C. Hanlon; R. A. Hoekstra	2020	Perceptions and experiences of stigma among parents of children with developmental disorders in Ethiopia: A qualitative study	Ethiopia: urban/ rural	*To explore perceptions and experiences of stigma among parents of children with DD in Ethiopia and examine the contributing and protective factors for internalised stigma based on the perspectives of the parents themselves.*	IDIs, N=18 in urban and rural context (F=14, M-4). Convenience sample- Selected in urban site from clinic, schools for children with DD, & in rural site via health worker
B. Tigere; J. C. Makhubele	2019	The experiences of parents of children living with disabilities at Lehlaba Protective Workshop in Sekhukhune district of Limpopo province	South Africa: rural	*The experiences and life circumstances faced by parents of children living with different types of disabilities.*	IDIs. N=14 (F=9, M=5) parents of children with disabilities attending workshop.

C. Masulani-Mwale; D. Mathanga; D. Silungwe; F. Kauye; M. Gladstone	2016	Parenting children with intellectual disabilities in Malawi: the impact that reaches beyond coping?	Malawi: urban & urban/ rural clinic	*To explore psychological experiences of parents caring for children with intellectual disabilities; understand their mechanisms of coping and their psychosocial needs in Malawi.*	10 FGDS (4 FGDs= M, 6 FGDs= F), 4 IDIs with parents with children with intellectual attending clinics.
C. Pretorius; J. Steadman	2018	Barriers and Facilitators to Caring for a Child with Cerebral Palsy in Rural Communities of the Western Cape, South Africa	South Africa: rural	*to explore the barriers and facilitators that caregivers of children with CP encounter through their daily caring roles in rural communities in SA.*	SSIs, N=15 (F=14, M=1). Purposive sampling, with families identified through cerebral palsy association and their contacts.
C. Singogo; M. Mweshi; A. Rhoda	2015	Challenges experienced by mothers caring for children with cerebral palsy in Zambia	Zambia: urban	*To explore the challenges that mothers who cared for children with cerebral palsy living in Zambia.*	SSIs, N=16 mothers attending rehab centre. Purposive sample.
D. Lamptey	2019	Health beliefs and behaviours of families towards the health needs of children with intellectual and developmental disabilities (IDD) in Accra, Ghana	Ghana: urban	*To explore the health beliefs and behaviours of families towards the health needs of children with intellectual and development and disabilities (IDD).*	N=22 (F=19, M=3). Convenience sample from author's own networks with 'key organisations'.
D. Tilahun; C. Hanlon; A. Fekadu; B. Tekola; Y. Baheretibeb; R. A. Hoekstra	2016	Stigma, explanatory models and unmet needs of caregivers of children with developmental disorders in a low-income African country: a cross-sectional facility-based survey	Ethiopia: urban	*To examine the stigma experiences, explanatory models, unmet needs, preferred interventions and coping mechanisms of caregivers of children with developmental disorders in Ethiopia.*	Questionnaire/SSI to caregivers of children with ASD and/or ID in two hospitals. caregivers (N = 102). No data on gender. Convenience sample from those attending child mental health clinics at hospital.
E. J. van der Mark; H. Verrest	2014	Fighting the odds: strategies of female caregivers of disabled children in Zimbabwe	Zimbabwe: urban	*To examine the resources and caring strategies of female caregivers*	Survey (N=61, F=61), random sample from NGO database. 4 participatory workshops (n=28), IDIs (n=22).
E. J. van der Mark; I. Conradie; C. W. Dedding; J. E. Broerse	2019	'We create our own small world': Daily realities of mothers of disabled children in a South African urban settlement	South Africa: urban	*To provide an in-depth understanding of the perspectives and experiences of South African mothers living in poverty with a disabled child.*	N= 30 caregivers (F=30) from a day-care centre. Purposive sample. 15 semi-structured interviews and 24 participatory group sessions. Parents attending a day-centre service & through word of mouth/community leaders.

E. J. van der Mark; I. Conradie; C. W. M. Dedding; J. E. W. Broerse	2019	Exploring adaptation and agency of mothers caring for disabled children in an urban settlement in South Africa: A qualitative study	South Africa: urban	To explore how mothers of disabled from a poor urban settlement in South Africa manoeuvre, adapt, act and react.	N=30 (F=30, mothers, grandmothers, sisters) 24 sessions direct data collection, other sessions on design and implementation of project (data through observation). Observation. 15 SSIs. Parents attending a day-centre service & through word of mouth/community leaders.
F. N. Machuki; G. Munyoki; P. Kabue	2016	Care of children with cerebral palsy among guardians attending OT clinic at Kenyatta National Hospital, Nairobi city county, Kenya	Kenya: urban (tertiary hospital)	*To determine level of knowledge of cerebral palsy among guardians, the psycho-social experiences and challenges among guardians of children with cerebral palsy.*	Survey & FGDs. N=285 CGs (f=285) of children with CP, unclear number of FGDS, families attending hospital.
G. Barlindhaug; E. Umar; M. Wazakili; N. Emaus	2016	Living with disabled children in Malawi: Challenges and rewards	Malawi: rural		Case study, ethnographic design over 4.5 month. n=2 families with a child with a severe disability (one child with CP)* 4 families in total, but data presented on 2. Families sampled through register of outreach rehabilitation programme.
G. G. Nyante; C. Carpenter	2019	The experience of carers of children with cerebral palsy living in rural areas of Ghana who have received no rehabilitation services: A qualitative study	Ghana: rural	*To explore the experiences of carers of children with cerebral palsy living in rural areas of Ghana who have received no rehabilitation services.*	SSIs, N=12 caregivers (F=10, M=2) of children with CP. Purposive sample through community health nurses.
G. Namazzi; C. Hanson; C. Nalwadda; M. Tetui; M. Nampijja; P. Waiswa; J. K. Tumwine; H. Hildenwall	2020	Caring for children with neurodevelopmental disability: Experiences from caretakers and health workers in rural eastern Uganda	Uganda: rural		IDIs. N= 14 caretakers (no data on gender) of infants with severe neurodevelopmental disability, Purposive sample from data from prior survey, n=5 health workers.

Geere, J., Gona, J., Omondi, F., Kifalu, M., Newton, C. & Hartley, S	2013	Caring for children with physical disability in Kenya: potential links between caregiving and carers' physical health. Child: care, health and development, 39, 381-39	Kenya: rural	*To explore the potential links between providing care of a child with moderate-severe motor impairments and the physical health of carers, in a low-income country/to identify ways to improve the situation for carers and their families.*	IDIS, clinical assessment, N=20 carers (F=17, M=3). Purposive sample from a range of sources; database, prior study, list of health service users.
J. A. Dogbe; J. D. A. Kyerematenng; M. P. Opoku; W. Nketsia; C. Hammond	2019	'There is family tension, but they understand…': familial and sibling relationships following the diagnosis of cerebral palsy in children in Ghana	Ghana: urban (tertiary hospital)	*To explore parents' experiences of raising children with CP, specifically focusing on the relationships between spouses and between children with CP and their typically developing siblings.*	SSI 40 parent (F=35, M=5) purposively selected at tertiary hospital.
J. den Besten; M. T. Cornielje; H. Cornielje; D. N. Botwey	2016	Supporting Parents in Caring for Children with Disability in Ghana	Ghana: urban/ rural	*To assess the factors that influence the well-being of caregivers and their children with a disability, in a rural and an urban site in Ghana.*	Participatory tools; PhotoVoice & Cantril ladder. N=25 parents (F-19, M=6) of children with different disabilities. Purposive sample - in urban site from families attending physiotherapy, in rural site not attending services.
J. Gona; V. Mung'ala-Odera; C. Newton; S. Hartley	2011	Caring for children with disabilities in Kilifi, Kenya: What is the carer's experience?	Kenya: urban	*What challenges do carers of children with moderate and severe disabilities in Kilifi face? How do they cope with these challenges?*	IDIs. N=35 with 20 carers (no data on gender), 10 community members, 5 teachers, home observation. Purposive sample identified from wider neurological survey.
J. K. Gona; C. R. Newton; K. K. Rimba; R. Mapenzi; M. Kihara; F. V. Vijver; A. Abubakar	2016	Challenges and coping strategies of parents of children with autism on the Kenyan coast	Kenya: rural/ urban	*What are the challenges faced by parents of children with autism on the Kenyan coast? What coping strategies do these parents apply?*	Total: N=103, n=37 IDIs, 8 FGDs parents of children with autism & professionals (no gender breakdown) in regular contact with these parents.

J. Muderedzi; A. H. Eide; S. H. Braathen; B. Stray-Pedersen	2017	Perceptions and treatment of children with cerebral palsy among the Tonga of Binga in Zimbabwe	Zimbabwe: rural	*Explores the link between disability perceptions and treatment among the Tonga of Binga through their disabled children.*	Longitudinal (2005-2013), Purposive sample of N=53 families (no date on gender) selected from larger survey of families. Ethnographic design with IDIs, observation (n=20), FGDs (n=10). Sampling frame unclear.
Kyerematen, J. D. A., A. Edusei, J. A. Dogbe, M. P. Opoku, W. Nketsia, C. Hammond and S. A. Afriyie (2019).	2019	Experiences of primary caregivers of children with cerebral palsy across the trajectory of diagnoses in Ghana	Ghana: urban (tertiary hospital)	*To explore the experiences of primary caregivers across the trajectory of the diagnosis (before, during and after) of CP in the setting of a tertiary hospital.*	SSIs, N=40 (F=35, M=5) CG of children with CP, purposive sample of those attending hospital, interviewee before/during/after diagnosis.
M. Gladstone; M. McLinden; G. Douglas; E. Jolley; E. Schmidt; J. Chimoyo; H. Magombo; P. Lynch	2017	'Maybe I will give some help…. maybe not to help the eyes but different help': an analysis of care and support of children with visual impairment in community settings in Malawi	Malawi: urban/ rural	*This study aims to identify facilitators and barriers to the provision of a developmental stimulation programme for children with VI in rural and urban Malawi.*	10 home observations, n=20 IDIs carers of children with VI, 6 FGDs (no data on gender of participants). Purposive sampling from range of sources: teachers, community workers, clinics.
M. Mofokeng; A. E. van der Wath	2017	Challenges experienced by parents living with a child with attention deficit hyperactivity disorder	South Africa: urban	*To explore parents' experiences of living with a child with attention deficit hyperactivity disorder (ADHD)*	IDIs, N=10 (F=8, M=-2) convenience sample of parents with children diagnosed with ADHD receiving outpatient treatment.
M. Oti-Boadi	2017	Exploring the Lived Experiences of Mothers of Children with Intellectual Disability in Ghana	Ghana: urban	*This study explored the experiences of mothers of children with intellectual disability in Ghana.*	SSIs: N=11 mothers of children with intellectual disability that attended a special school.
M. Zuurmond; V. Nyapera; V. Mwenda; J. Kisia; H. Rono; J. Palmer	2016	Childhood disability in Turkana, Kenya: Understanding how carers cope in a complex humanitarian setting	Kenya: rural	*To understand the lived experiences of children with disabilities and their caregiver in a humanitarian setting.*	IDIs. N=31 caregivers of children with a wide range of disabilities. F= 27, M-4. Purposive sample from NGO database & snowballing.

Mcnally, A. & Mannan, H.	2013	Perceptions of caring for children with disabilities: Experiences from Moshi, Tanzania.	Tanzania: urban	*The objective of this research was to gain an insight into how having a child with a disability impacts upon participants lives and to examine both negative and positive experiences of care through the use of qualitative methods*	SSIs N=14 carers (no data on gender) convenience sample attending a day care centre.
N Muthukrishna; H. Ebrahim	2014	Motherhood and the disabled child in contexts of early education and care	South Africa: unclear if urban/ rural		IDIs with 6 carers (F=6). Identified through 2 NGO centres for the disabled.
P. Patel; J. Baier; E. Baranov; E. Khurana; C. Gambrah-Sampaney; A. Johnson; B. Monokwane; D. Bearden	2017	Health beliefs regarding pediatric cerebral palsy among caregivers in Botswana: A qualitative study	Botswana: urban		SSIs, N=62 caregivers (F=60, M=2) from hospital inpatient and outpatient sites, data identified from larger study.
P. Sandy; J. Kgole; T. Mavundla	2013	Support needs of caregivers: Case studies in South Africa	South Africa: rural	*To investigate the support needs of caregivers caring for children with learning disabilities.*	Case study: Purposive sample of 3 families (includes one female headed household) of children with learning disabilities who have attended clinic for > 10 years.
R. A. Hepperlen; P. Rabaey; A. Ament-Lemke; H. Manley	2021	Caring for a child with a disability in a Zambian community: A study using photo-elicitation	Zambia: urban	*To explore experiences of caregivers of CWD through participant-driven photo-elicitation, in a low-income subdistrict of Lusaka.*	Photo-elicitation. N=10 parents of child with disability. (F=9, M=1). Purposive sample - members of a support program.
S. Hartley; P. Ojwang; A. Baguwemu; M. Ddamulira; A. Chavuta	2005	How do carers of disabled children cope? The Ugandan perspective	Uganda: urban & rural	*To understanding family coping strategies.*	IDIs N=52 families (F=24, M=2, M+F= 5, siblings/guardians=7 (no gender detailed) with children with disabilities from five impairment groups, observation. Purposive sample from CBR programme.
S. Mkabile; L. Swartz	2020	Caregivers' and parents' explanatory models of intellectual disability in Khayelitsha, Cape Town, South Africa	South Africa: urban		SSIs with 20 caregivers (F=17, M=3) Purposive sample of those attending using in-patient and out-patient services.

S. Nakamanya; G. E. Siu; R. Lassman; J. Seeley; C. J. Tann	2015	Maternal experiences of caring for an infant with neurological impairment after neonatal encephalopathy in Uganda: a qualitative study	Uganda: urban	*Investigated maternal experiences of caring for a child affected by neurological impairment after neonatal encephalopathy (NE) ('birth asphyxia') in Uganda*	IDIS, FGDS, mother attending hospital, N=19 (F=19). Purposive sample from larger survey data.
Mkabile, S., K. L. Garrun, M. Shelton and L. Swartz (2021).	2021	African families' and caregivers' experiences of raising a child with intellectual disability: A narrative synthesis of qualitative studies." African Journal of Disability 10.	Africa: Nigeria, Tanzania, DRC, Kenya, Ghana, Malawi, Zambia, Namibia, Ethiopia	*To investigate experiences of caregivers and parents of children with ID in Africa*	Scoping Review: 9 studies- Narrative synthesis of findings.

Appendix 4: LSHTM Ethical Approval

London School of Hygiene & Tropical Medicine
Keppel Street, London WC1E 7HT
United Kingdom
Switchboard: +44 (0)20 7636 8636

www.lshtm.ac.uk

Observational / Interventions Research Ethics Committee

Ms Maria zuurmond
Research Fellow
Department of Clinical Research (CRD)
Infectious and Tropical Diseases (ITD)
LSHTM

23 March 2015

Dear Maria

Study Title: Evaluating the impact of a community –based parent training programme for children with Cerebral Palsy in Ghana

LSHTM Ethics Ref: 8905

Thank you for responding to the Interventions Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

Approval is dependent on local ethical approval having been received, where relevant.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document Type	File Name	Date	Version
Information Sheet	Childrens informationsheet GHana19Dec2	09/01/2015	1
Information Sheet	GhanaNPL-Consent_form_parents_and_children-Final-IO-Eng-9thJan	09/01/2015	1
Investigator CV	CV Sarah Polack	09/01/2015	1
Investigator CV	CVMariazuurmond	09/01/2015	1
Information Sheet	GhanaNPL-Information_sheet_parents-jan9th	09/01/2015	1
Protocol / Proposal	Proposalfinal9thjan	09/01/2015	1
Protocol / Proposal	family Impact versionPed	09/01/2015	1
Protocol / Proposal	PedsQL4-0Ch	09/01/2015	1
Protocol / Proposal	PedsQL-5-7-P_1	09/01/2015	1
Protocol / Proposal	CPchild sickkids -QoLquestionnaire	09/01/2015	1
Protocol / Proposal	Case study topic guide draft 1	09/01/2015	1
Covering Letter	A covering letter update20thMarch	20/03/2015	one
Protocol / Proposal	Theory of change 24th Feb	20/03/2015	version one
Protocol / Proposal	Proposalwith modifications20thMarch	20/03/2015	two

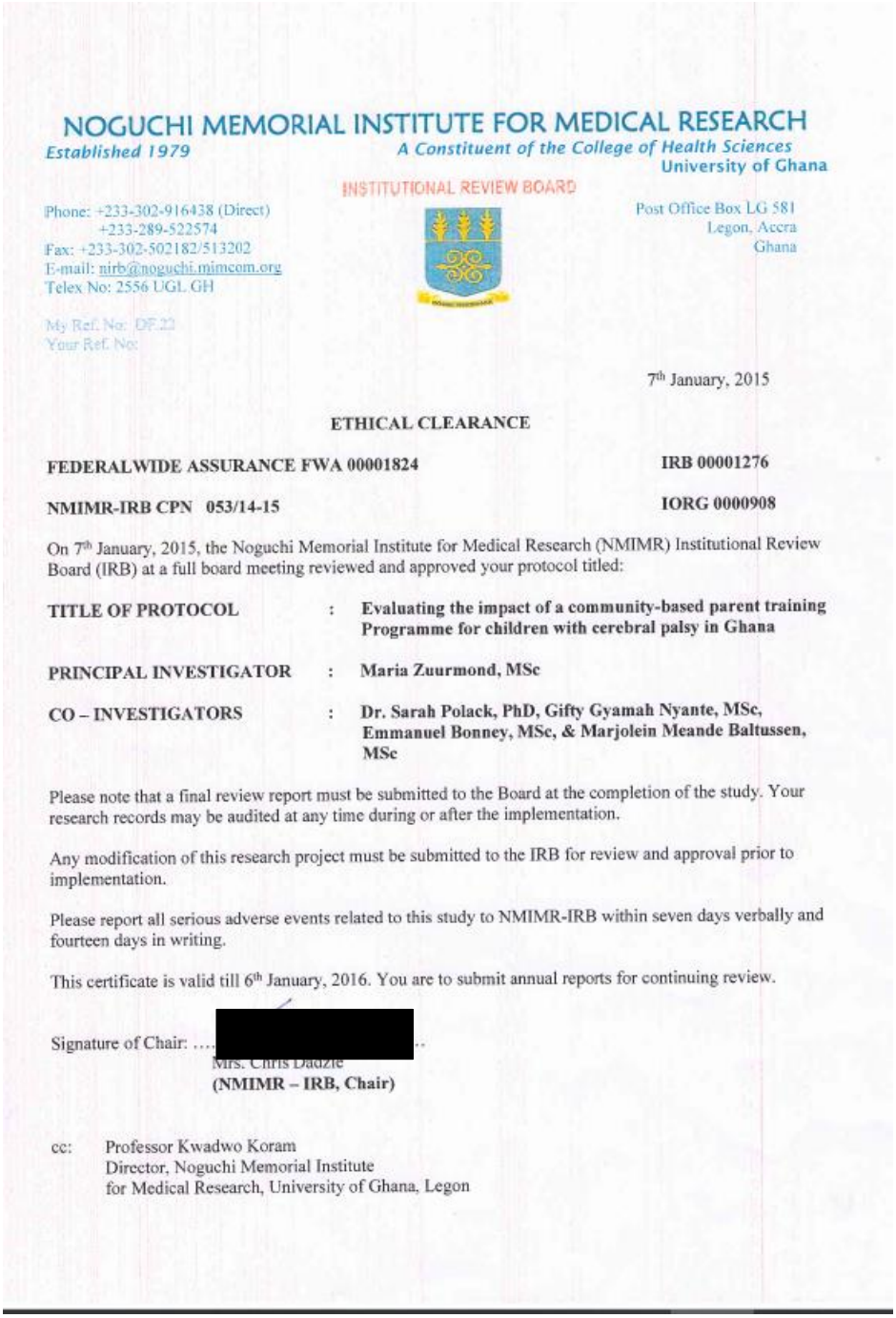
After ethical review

The Chief Investigator (CI) or delegate is responsible for informing the ethics committee of any subsequent changes to the application. These must be submitted to the Committee for review using an Amendment form. Amendments must not be initiated before receipt of written favourable opinion from the committee.

The CI or delegate is also required to notify the ethics committee of any protocol violations and/or Suspected Unexpected Serious Adverse Reactions (SUSARs) which occur during the project by submitting a Serious Adverse Event form.

An annual report should be submitted to the committee using an Annual Report form on the anniversary of the approval of the study during the lifetime of the study.

Appendix 5: Ghana Ethical approval



NOGUCHI MEMORIAL INSTITUTE FOR MEDICAL RESEARCH
Established 1979
A Constituent of the College of Health Sciences
University of Ghana

INSTITUTIONAL REVIEW BOARD

Phone: +233-302-916438 (Direct)
+233-289-522574
Fax: +233-302-502182/513202
E-mail: nirb@noguchi.mimcom.org
Telex No: 2556 UGL GH

Post Office Box LG 581
Legon, Accra
Ghana

My Ref. No: DF.22
Your Ref. No:

7th January, 2015

ETHICAL CLEARANCE

FEDERALWIDE ASSURANCE FWA 00001824 **IRB 00001276**

NMIMR-IRB CPN 053/14-15 **IORG 0000908**

On 7th January, 2015, the Noguchi Memorial Institute for Medical Research (NMIMR) Institutional Review Board (IRB) at a full board meeting reviewed and approved your protocol titled:

TITLE OF PROTOCOL : **Evaluating the impact of a community-based parent training Programme for children with cerebral palsy in Ghana**

PRINCIPAL INVESTIGATOR : **Maria Zuurmond, MSc**

CO – INVESTIGATORS : **Dr. Sarah Polack, PhD, Gifty Gyamah Nyante, MSc, Emmanuel Bonney, MSc, & Marjolein Meande Baltussen, MSc**

Please note that a final review report must be submitted to the Board at the completion of the study. Your research records may be audited at any time during or after the implementation.

Any modification of this research project must be submitted to the IRB for review and approval prior to implementation.

Please report all serious adverse events related to this study to NMIMR-IRB within seven days verbally and fourteen days in writing.

This certificate is valid till 6th January, 2016. You are to submit annual reports for continuing review.

Signature of Chair: ....[redacted]..
Mrs. Chris Dadzie
(NMIMR – IRB, Chair)

cc: Professor Kwadwo Koram
Director, Noguchi Memorial Institute
for Medical Research, University of Ghana, Legon

Appendix 6 PedsQL™ Family Impact Module

PedsQL™

Family Impact Module

Version 2.0

PARENT REPORT

DIRECTIONS

Families of children sometimes have special concerns or difficulties because of the child's health. On the following page is a list of things that might be a problem for **you**. Please tell us **how much of a problem** each one has been for **you** during the **past ONE month** by circling:

0 if it is **never** a problem
1 if it is **almost never** a problem
2 if it is **sometimes** a problem
3 if it is **often** a problem
4 if it is **almost always** a problem

There are no right or wrong answers.
If you do not understand a question, please ask for help.

*In the past **ONE month**, as a result of your child's health, how much of a problem have **you** had with…*

PHYSICAL FUNCTIONING *(problems with…)*	Never	Almost Never	Some-times	Often	Almost Always
1. I feel tired during the day	0	1	2	3	4
2. I feel tired when I wake up in the morning	0	1	2	3	4
3. I feel too tired to do the things I like to do	0	1	2	3	4
4. I get headaches	0	1	2	3	4
5. I feel physically weak	0	1	2	3	4
6. I feel sick to my stomach	0	1	2	3	4

EMOTIONAL FUNCTIONING *(problems with…)*	Never	Almost Never	Some-times	Often	Almost Always
1. I feel anxious	0	1	2	3	4
2. I feel sad	0	1	2	3	4
3. I feel angry	0	1	2	3	4
4. I feel frustrated	0	1	2	3	4
5. I feel helpless or hopeless	0	1	2	3	4

SOCIAL FUNCTIONING *(problems with…)*	Never	Almost Never	Some-times	Often	Almost Always
1. I feel isolated from others	0	1	2	3	4
2. I have trouble getting support from others	0	1	2	3	4
3. It is hard to find time for social activities	0	1	2	3	4
4. I do not have enough energy for social activities	0	1	2	3	4

COGNITIVE FUNCTIONING *(problems with…)*	Never	Almost Never	Some-times	Often	Almost Always
1. It is hard for me to keep my attention on things	0	1	2	3	4
2. It is hard for me to remember what people tell me	0	1	2	3	4
3. It is hard for me to remember what I just heard	0	1	2	3	4
4. It is hard for me to think quickly	0	1	2	3	4
5. I have trouble remembering what I was just thinking	0	1	2	3	4

COMMUNICATION *(problems with…)*	Never	Almost Never	Some-times	Often	Almost Always
1. I feel that others do not understand my family's situation	0	1	2	3	4
2. It is hard for me to talk about my child's health with others	0	1	2	3	4
3. It is hard for me to tell doctors and nurses how I feel	0	1	2	3	4

*In the past **ONE month**, as a result of your child's health, how much of a problem have **you** had with…*

PedsQL 3.0 - Parent Family Impact 6/04 Not to be reproduced without permission Copyright © 1998 JW Varni, PhD. All rights reserved

WORRY *(problems with…)*	Never	Almost Never	Some-times	Often	Almost Always
1. I worry about whether or not my child's medical treatments are working	0	1	2	3	4
2. I worry about the side effects of my child's medications/medical treatments	0	1	2	3	4
3. I worry about how others will react to my child's condition	0	1	2	3	4
4. I worry about how my child's illness is affecting other family members	0	1	2	3	4
5. I worry about my child's future	0	1	2	3	4

DIRECTIONS

Below is a list of things that might be a problem for **your family**. Please tell us **how much of a problem** each one has been for **your family** during the **past ONE month.**

*In the past **ONE month**, as a result of your child's health, how much of a problem has **your family** had with…*

DAILY ACTIVITIES *(problems with…)*	Never	Almost Never	Some-times	Often	Almost Always
1. Family activities taking more time and effort	0	1	2	3	4
2. Difficulty finding time to finish household tasks	0	1	2	3	4
3. Feeling too tired to finish household tasks	0	1	2	3	4

FAMILY RELATIONSHIPS *(problems with…)*	Never	Almost Never	Some-times	Often	Almost Always
1. Lack of communication between family members	0	1	2	3	4
2. Conflicts between family members	0	1	2	3	4
3. Difficulty making decisions together as a family	0	1	2	3	4
4. Difficulty solving family problems together	0	1	2	3	4
5. Stress or tension between family members	0	1	2	3	4

Appendix 7: PedsQL™ Family Impact version: Kusaal cognitive field-testing report

Date: 18/6/15-21/6/15 (initial tests, followed by focus group with Mr. Fritz and Isaaka, followed by field testing followed by additional work with Mr. Johnson and Isaaka focus group)

Forwards Translation: Grady Institute

Initial Reconciliation with Mr. Fritz (University. of Ghana hired linguist) and Isaaka (Bawku native), David O'Banion (LSHTM) and Sandra Asante (U. Ghana)

Second Review with Mr. Johnson (CBM coordinator of CBR and former Kusaal Language Institute instructor) and Isaaka, David O'Banion (LSHTM) and Sandra Asante (U. Ghana)

DƆLISUG SUOYA

Biisyidimɛɛntimɔrpʊtɛn'ɛsʊmasieba bɛɛ yɛlmugisabiiglaafiyɛla. Yɛlsiebabɛlakkir kanɛ dɔl la ni ka **fʊn**yɛltun'ebɛani. Kpɛ'ɛŋimyɛliti**yɛl la zɛmsi'em**nɛyɛlwʊsaansi'em tis **fʊ**nwadigyinne kanɛ gaad la ni. buoɛnmgiligyɛl la.

Please be aware that in Kusaal, Windows software typically merges all the words together like you may see above. Please view the PDF version for the printed and field use version. This file is for discussion of the field testing

0 Li ya'a**ka'**yɛlkpankpanɛ

1 Li ya'aɛɛnti**Pʊ an**yɛllɛ

2 Li ya'aɛɛnti an yɛl**sansi'a**

3 Li ya'aɛɛnti anYɛL**tu'ombi'el, tu'ombi'él**

4 Li ya'aɛɛnti an yɛl**saŋawʊsa**

Gandigirsi'akae an sʊm bɛɛ bɛ'ɛdɛ "Feel Free"

Fʊya'apʊgban'ebu'osʊgsi'agbinnɛ, kpɛ'ɛŋimsɔs ka ba sʊŋif

In the past ONE month, as a result of your child's health, how much of a problem have you had with…

A note on field. In the Kusaal speaking region, in our field testing we encountered 7 women with children with disabilities. 4 had children with apparent cerebral palsy, and the 5th did not bring her child to the interview. The Kusaal-speaking region does not have high rates of literacy, so this questionnaire was administered orally in every instance. The 7 women for field testing varied in ages from early 20s to 60s (grandmother/caregivers) and 1 woman had attended some high school. Because the questionnaire was orally administered, each item was adapted to direct the question in the 2nd person, ie: How often do you have a problem with.... After a small number of practice interviews, we realized that we first needed to ask Y/N question. It was explained to us that one of the interviewed caregivers had a difficult time understanding that we were asking to rate the frequency of the problem with the "How often" question stem. Then, we changed to asking "Do you have a problem with..." and clarified the frequency from there. See below for discussion on frequency.

Frequency of a problem proved a remarkable challenge in Kusaal. There were a few reasons that we were eventually able to identify. The first technique we attempted was a visual of the scale you see below, to help with a concrete tactile anchor for which to indicate the degree of severity. This was very confusing to the caregivers and was stopped after 1 day of field testing (3 caregivers completing full field interviews). The next remarkable problem is that "Sansia" meaning "sometimes" poses three issues. The first is that the best way to pose a question in Kusaal is "Do you sometimes have a problem with..." Yielded, "Yes, sometimes" as a response. When we tried to clarify how frequently, sometimes would be the response. When asked how many times a week it may happen, we learned that the problem could happen every day and still be considered "sometimes." It was difficult for our translator to remove "sometimes" from the question stem and therefore it was difficult that we always needed to clarify the response, "sometimes." The second problem with "sometimes" is that as described above it describes, in Kusaal, an event that happens as rarely as monthly to almost always. Once the caregiver chose "sometimes," it was difficult for them to consider a daily problem "almost always." More on that below. The third problem with "sometimes" may involve our use of a male translator and the social bias of how to respond to a man. A woman in this region is not to question or trouble a man with her problems (more on this below in the items), and the best social response if admitting a problem is "sometimes." It was only after several field interviews that we understood the degree of trouble that "sometimes" would give us. We were unable to avoid it, as there isn't a commonly-used expression in its place. The next trouble comes with "always," or rather, "almost," as there is no word in Kusaal for "almost." "Always," similarly, is not an acceptable answer in very many circumstances. Part of the problem, as explained by our two Kusaal readers and writers used in a focus group, was that it is difficult for people to moderate answer choices in between the extremity of Always and the Vagueness of "Sometimes," so therefore "Sometimes" is used as the response. We discussed better choices for "often" and "almost never," though it was in question whether these choices would be used. In field testing, they were not commonly endorsed. So, we devised a frequency system by which to check. Never happens = never a problem. Happens but is infrequently so not considered a problem = almost never; happens enough to be a problem but less than 2-3 times per week = sometimes; Happens between 2-4 times per week and

considered a "regular" problem = often; happens 4 times or more = almost always. For several items this does not apply.

Parents caught on to this system somewhat well and began answering questions with "yes its a problem that happens ___ times per week," which helped our efficiency greatly. This system does not work for every question, however, and works best with activities of daily living (house chores) than infrequent events (naming ceremonies/social events). Several items, also, occur in a person's life relatively infrequently or deal more abstractly - like "I worry about my child's medical treatments not working," when a child might very infrequently see a doctor. For these less often events, we askede about the frequency of worry/problem when the event actually happens, rather than per month. So, if a mother NEVER gets time to attend . a naming ceremony because she can't find the time (or support, or energy in those cases) then it is "almost always" a problem. Again, the lifestyles of the subjects affects the data but in this consistent way we carried out the field tests.

The next problem in Kusaal is that the language is NOT standardized, and only within the last decade has it been taught. Therefore, there are village to village differences in dialect and house to house differences in vocabulary. This is a challenge to our translator as asking the question in our standardized translation is not consistently understood, so clarification ensues. We therefore adopted a series of clarification examples to set situations for items. These, too, could challenge an uneducated caregiver to make an answer on the example ONLY, rather than the example as a general idea. When we used several examples to frame the general idea, caregivers would respond to either all of the examples in kind or pick one example and explain that situation. This was laborious for the translators. Mr. Johnson would then have to judge the caregivers understanding of the general idea by the quality of the caregivers response and clarify as needed. Below is a discussion on each item nested within the item. The frequency in which the question was understood is attempted to be described. Field testing took place with Mr. Fritz, a linguist employed by U. of Ghana. When Mr. Fritz became ill with malaria, Mr. Johnson (a Garu local and former director of the Kusaal Language Institute) took over and provided additional ideas about the presentation of some of the items. The greatest change brought about by Mr. Johnson was changing each question to a directed yes or no question by using the word, "Fu." This prevented the confusion over the abstract statement in the first person voice.

NIŊGBINA TUUMA (li yɛlaanɛ...)	Kpankpan	Nwɛnɛkpankpan	Sansieba	Tu'ombi'el	Nwɛnɛsangawʊsa
1. Li nwɛnɛ m gɛnɛdabisir la pʊʊgin. Item was often understood. Occasional clarification was required about *when* during the day. This was not critical to the item, but we did clarify when necessary that it meant roughly breakfast to mid afternoon.					
2. M ya'aduoebɛogʊn li nwɛnɛ m gɛnɛ Often understood. Once the expression was related back to us that the mother feels “as if I was beaten during the night,” which sounded extreme but is a local expression for this feeling. Another parent clarified that when she wakes up she wishes the day wasn’t breaking. Again this is consistent with the item.					
3. M ya'abɔɔdi m tʊmsi'ela li nwɛnɛ m gɛnɛnɛ. This item involves housework in Kusaal, as the “things I enjoy doing,” have to be included in “things you are going to do during the day,” or “things you have planned for the day.”					

4. M nyɛtizugzabir (Kusaal edited by Mr. Johnson) Easily understood
5. M niŋgbiŋ ka' paŋa (Kusaal edited by Mr. Johnson) Not always understood. Explanation from caregivers included feeling ill, feeling sleepy, and not sleeping well. Clarification provided to Mr. Johnson in English was “the body feels weak, no strength.”
6. M pʊʊgʊɛɛntizabid. (Kusaal edited by Mr. Johnson) Not well understood. We clarified using a kusaal expression that translates literally to “Do you feel as if you are ill but you cannot exactly say what is wrong?” We did also ask whether caregivers were so tired that they experienced symptoms in the abdomen – like lack of appetite or nausea. This was endorsed in one occasion but not well understood. It was explained in our focus group that the Kusaal expression (above) is more commonly reported. We used that during our testing and if needing clarification we asked the question about the abdominal symptoms.

PUTƐN'ƐRT UUMA (li yɛlaanɛ...)	Kpankpan	Nwɛnɛkpankpan	Sansieba	Tu'ombi'el	Nwɛnɛsangawʊsa
1. Li nwɛnɛ m ya'amian'adnɛ (Kusaal *replaced* by Mr. Johnson with more appropriate phrase). Do you worry about things? Understood well but clarification when needed was provided, “Do you feel you are worried about what is happening with your child?”					
2. Li nwɛnɛ m sʊnfʊsa'amnɛ. Understood well.					
3. M sʊnfʊpɛligid. Understood well.					
4. M ya'amwidigidnɛ. Not understood well. The clarification responses by caregivers were not always related to frustration, but there is no exact word for frustration. “Do you feel as if you have hit a wall.” was used to clarify – “when considering all that you have done and been					
5. Li nwɛnɛ m ka' ti'ir bɛɛ sʊŋida. Not well understood. The word “helpless” is too often confused with “helper, or support person.” The clarification became “Do you have no hope?” This was responded most often by “I have hope, I have given the problem up to God.” This required laborious clarification to find out how difficult it was to maintain hope. If this was not understood, they would be asked how often they felt that they were giving the problem up to God and not struggling with the problem anymore – ie: helpless to change the					

LA'ASUG TUMMA (li yɛlaanɛ...) These questions were somewhat well understood.	Kpankpan	Nwɛnɛkpankpan	Sansieba	Tu'ombi'el	Nwɛnɛsangawʊsa
1. Li nwɛnɛ m bakkinɛtaaba la. Reasonably well understood. Clarification, when they said no, was rarely needed but usually consisted of re-asking the question.					
2.Li tɔinɛnɛ man napaamsʊŋiri m taabani This question was usually answered in the explanation of the above question. Specifically, we would clarify the frequency of the problem. When required, we would also ask how often the caregiver has a problem getting					
3. Li tɔinɛ man nanyɛsaŋala'asnɛ m taaba. When the caregiver responded in a way that did not involve the time, we would clarify with emphasis on TIME. Social activities would be offered as examples: naming ceremonies, weddings, funerals. Caregivers often *never* got to					
4. M pʊmɔrpaŋila'asidnɛ m taaba. When requiring clarification, it meant the caregiver was still focused on *time* rather than energy. Often caregivers endorsed that they would have energy to attend if someone would ever care for the child.					

TIƐNR TƱMMA (li yɛlaanɛ...)	Kpankpan	Nwɛnɛkpankpan	Sansieba	Tu'ombi'el	Nwɛnɛsangawʊsa
1. Li tɔinɛtisimnɛ m ba' nabɛsi'elnamin. Clarification examples: For instance, if you are working on something and your child needs you, do you get distracted because of your child. Does that happen often? For instance, cooking was the most common instance used. Some caregivers would identify their occupation as a task that they *could not be distracted from*. We would clarify that though *the occupationi* was never a problem, did the child distract them from other things? Was the child's concerns often on the caregiver's mind? Was this					
2.Li tɔinɛtisimnɛ man natɛnrnidibiyɛttimsi'el Variably well understood on the first go. The example was used by Mr. Johnson – if someone tells you something to do will you have difficulty remembering it later in the day?					
3. Li tɔinɛtisimnɛ man natɛnr ban yɛlimsi'elnannanna; because of it's relationand proximity to the previous question, this required clarification. The example was if you are talking with someone and your child needs you, do you have to respond to the child then ask the person					
4. Li tɔinɛtisimnɛ man natɛn'ɛstɔ'ɔtɔ; Required clarification – is it difficult for you to think through a problem quickly and clearly to the solution? What if your child needs you when					
5. Li tɔinɛtisimnɛ man natiɛn man tɛn'ɛsidinsi'elnannana; clarification was required: if you have gone into a room to pick something, do you forget what you were doing when you get					

SƆNSƱG LABAYA *(li yɛlaanɛ)*	Kpankpan	Nwɛnɛkpankpan	Sansieba	Tu'ombi'el	Nwɛnɛsangawʊsa
1. inwɛnɛsiebapʊgban'ad man yidimyɛlagbinnɛ in Kusaal, this always required clarification. The response indicated that "Yes, people are aware that I have a child with disability." Clarification: We would ask if people knew how the caregiver worried about the child. If needed, we would then use caregiver-supplied examples of their worries and ask if people know how difficult it was for the caregiver to be worried about these things. Of special note, by this point, it was clear whether the family was being supportive and helping the caregiver – which often was not the case. These caregivers, when asked about whether people understood something about the family, had a difficult time responding *on behalf of the family* sometimes saying, "How should I know what the other members of my family feel?" Also of note, some caregivers felt uncomfortable reporting what anyone other than themselves probably felt or understood, meaning these and other questions that ask the					
2. Li tɔinɛnɛ man napian' m biigwiim la yɛla Always required clarification. Most commonly, caregivers would say that people ALWAYS ask them "what is wrong with your child," so they considered that talking with others. We would clarify by asking whether it is difficult *to discuss* your child's condition. If still not well understood, we would ask whether it *bothers* the caregiver when people ask those questions, or when family members talk about the child.					

3. Li tɔinɛ man nayɛldu'atanɛnɛɛs m biigwiim la yɛla Often required clarification. Parents would say that it is not difficult. We would then ask when the last time they went to the hospital (often for malaria) could they ask doctors *why can my child not walk*. How often did they want to ask this question but didn't. Again the frequency of visiting a health centre affected the response, but we weighed the frequency of the problem based on the frequency in which it happened relative to the occurrence of the event (ie: everytime i go to the hospital, I ask the doctors why my child cannot walk – this is never a problem). Again, it was

*In the past**ONE month**, as a result of your child's health, how much of a problem have **you** had with…*

DAAUŊ (li yɛlaanɛ...)	Kpankpan	Nwɛnɛkpankpan	Sansieba	Tu'ombi'el	Nwɛnɛsangawʊsa
1. M dauŋanɛ m zi' ye m biig la ti'ebʊg la tʊmbɛ. Often required clarification: Do you worry that your child's treatments are not improving the condition? Sometimes we clarified using caregiver-supplied examples of treatments – do you worry that these things you are doing for your child are not improving the condition? If still not well understood, especially if a caregiver that does not seek treatment for the condition, do you worry that there are not treatments for					
2. M dauŋanɛlinɛnadaami m biig la ti'ebʊg la nya'aŋ; Well understood. Do you worry about the negative effects (in Kusaal, "affects" implies negative.					
3. M dauŋanɛnidibinagɔsidi m biig la bɛllim la si'em. Somewhat well understood, but the response was often "I can't change what they do, so I do not worry." We would clarify whether they dislike the way people behave around their child in the market (often pregnant women avoid these children and mothers instruct their children to avoid the children.) Another common response was "They are always talking about my child." This was felt close to the intended response, though not directly "reacting," so we would ask the clarification above to determine if the others' behavior (including talking) bothered the caregiver					
4. M dauŋanɛ m biig la wiim la nataasninsiebasi'em. Somewhat well understood, but responses also included "how should I know the way my family thinks of my child?" We would clarify whether anyone in the family acts or talks differently because of the child. Does this					
5. M dauŋanɛ m biig la bɛogyɛla. Usually well understood. Sometimes the response was "God has given the condition and God can heal the condition, so it is not my worry." We would clarify, "Do you worry about what will happen to your child?"					
DAAR WUSA TUUMA (li yɛlaanɛ...) These questions being similar, this was a difficulty at times	Kpankpan	Nwɛnɛkpankpan	Sansieba	Tu'ombi'el	Nwɛnɛsangawʊsa
1. Yin tʊʊmazaŋidisaŋanɛpaŋpamm Clarification 1) Housework = family activities, but including the whole family. Again, when the caregiver received no support, answering on behalf of the family was difficult. Second clarification would be farming, which is undertaken by a large majority of households in the kusaal region. Does the family's obligations and work					
2. Ya'akaenanaae yin tʊʊmaa. Same as above, same examples and problems but with emphasis on TIME					
3. gɛɛnlisbɛnɛnɛfʊnnanaae yin tʊʊma. Same as above, with emphasis on ENERGY/STRENGTH. Caregivers rarely were able to comment on someone else's level of energy.					
YIN SUZUOR (li yɛlaanɛ...)	Kpankpan	Nwɛnɛkpankpan	Sansieba	Tu'ombi'el	Nwɛnɛsangawʊsa
1. Yidiminapʊsɔnsidnɛtaabaa. Required clarification often. "No, we talk about things." = common response. Do the members of your household interact well? When you talk about the child's condition, is communication different or difficult? "We don't talk about the					

2. Yidiminamɔrnɔŋgbanwa'arnɛtaaba. Often this question had been answered previously so clarification was offered with the question stem using caregiver-supplied examples. If otherwise needed, we would ask whether there were arguments about the child. A note here pertaining to the remaining questions: women are not supposed to question men in this culture. We would have to clarify if there was "never" a problem because the caregiver was not supposed to question the men's decisions (so therefore no arguing). We'd then ask if the caregiver would have liked to have been part of the decisions, so is that a worry or problem? Also of note, Mr. Johnson did especially well with these questions in rarely evoking such a
3. Lin natɔi tis yidimnɛ ban nala'asigban'e. Required clarification in the above instances. If the male/female issue wasn't the stumbling block and the answer was "never" in a family that the caregiver had already reported great conflict, we would ask whether decisions about the child's care or treatment caused difficulty
4. Lin natɔinɛyidiminanyaŋimaalyɛl Same as above
5. Yɛlmugisa bɛɛ yɛltɔɔdinabɛyidimsʊʊgin. Clarfication could be required as above. But also "because of the child's condition are there bad feelings between members of the household?" Usually by this point the caregiver had given ample examples of stress and tension. So we would use caregiver-supplied examples and ask about frequency.

Appendix 8: Baseline survey questionnaire

Enter Child's ID number _ _

Ghana Cerebral Palsy Project 2015
Questionnaire for Primary Caregivers of Subjects

A. Demographics

1 District (tick)			
1=	Agogo CP	6=	Dormaa
2=	Bawku CP	7=	Duayaw Nkwanta
3=	Bolga CP	8=	Garu-Tempane
4=	Langbensi	9=	Sirigu
5=	Dodowa		

2 Group Name (tick)			
1=	PHC & Physio Unit Agogo	6=	PHC & Physio Unit Dorma
2=	Bawku Physio unit	7=	Physio Unit Duayaw Nkwanta
3=	PHC Bolga	8=	Garu
4=	Presby HC Langbensi	9=	Afrikids (Sirigu)
5=	Dodowa		

3 Interviewer ☐ 1= Sandra ☐ 2= David ☐ 3= Other (specify) _____

4 Date (Day/Month/Year) _ _/_ _/_ _

5 Child's Study ID Number ☐☐

6 **Child's** Name _____

7 What is the **CHILD's** age (in years) ☐☐

8 What is the **CHILD's** gender? ☐ 1= male ☐ 2= female

Record **CHILD's** date of birth __ / __ / __ (day/ mo/ year)

Tick whether you *confirmed* child's age with some form of identification (insurance card, health record, etc) ☐ 1= confirmed ☐ 2= unable to confirm

note to interviewer: these questions below are about the **CAREGIVER** for the child

9 Does the person being interviewed (**caregiver)** live in the same household as the child? ☐ 0= NO ☐ 1= YES

10 **Caregiver's** name _____

11 What is the **CAREGIVER's** age (choose one)

Kuffour Era (2000+) voted Pres. Rawlings
Famine '83 = 32 yrs
Rawling's coup 1979 = 36 yrs
Death-Nkrumah ('72) alive during the Busia regime ('71) Nkrumah regime

☐ 1 15 - 20 years
☐ 2 21 - 25 years
☐ 3 26 - 30 years
☐ 4 30 - 40 years
☐ 5 40 - 60 years
☐ 6 61 years and up

12 **Caregiver's** gender (observe) ☐ 1= male ☐ 2= female

13 What is the caregiver's relationship to the child (tick) ☐ 1= mother ☐ 2= father ☐ 3= step parent ☐ 4= grandparent ☐ 5= sibling ☐ 6= relative ☐ 7= other (specify)_____

"I would now like to ask you some questions about your work"

14 Other than domestic work in the household, have you done any work in the *last* month? 0= NO 1= YES

15 What is your occupation; that is, what kind of work do you mainly do? (*note: even if not currently employed*)

16 If you do work, do you:
- 1= own/household business
- 2= work for a non-household member
- 3= household farm owned or rented by household
- 4= other: specify____
- 5= N/A: I don't work **ANSWER QUESTION 17 if NOT working**

17 IF you have **NOT WORKED** in the past month, what is the main reason? (SELECT ONLY ONE)
- 1 Student
- 2 Childcare/duties/work inside the house
- 3 Too old / retired
- 4 Incapable of working, physically
- 5 Incapable of working, mentally
- 6 Nobody would give me a job because my child is disabled
- 7 Long illness (>1 month)
- 8 I am looking for my first job
- 9 No jobs opportunities in the area
- ## Quit/suspended from job
- ## Other (specify)

Marital Status, Literacy and Education

"Now I would like to ask you a few questions about your living status and education"

18 What is your marital status?
- Married or living together
- Divorced/seperated
- Widowed
- Single - Never married/never living together

19 Have you ever attended school?
- 0= NO **if NO, skip to Q21**
- 1= YES

20 What is the highest level of education you completed?
- Primary (includes KG from 4yrs)
- Junior High
- Senior High
- Tertiary (including job training)

Household Economics

21 Does the caregiver own this home, rent it, or is there some other situation?
- 1= Owned by caregiver/household
- 2= rented by caregiver/household
- 3= Other(Specify)

22. Tick all objects that the caregiver owns (or the head of household owns)

1 Radio	6 Mattress	11 Computer	16 Motorcycle
2 Clock or watch	7 Cot or Bed	12 DVD/VCD	17 Animal-drawn cart
3 Color TV	8 Table	13 Electric Fan	18 Car/Truck
4 Electricity/Lights	9 Chair	14 Telephone	19 Ownership of livestock
5 Sewing Machine	10 Refrigerator	15 Bicycle	

Enter Child's ID number _ _

Ghana Cerebral Palsy Project 2015
Questionnaire for Primary Caregivers of Subjects

B. Household Information

HOUSEHOLD DEFINITION: living in the household most days for the past 6 months, sharing meals most days the past 6 months (ie: eating from the same pot),

2 Is the caregiver the head of the household?
household head must live in household

☐ 0= NO
☐ 1= YES **if YES, skip to Q6**

3 If NO, Who is the HEAD OF HOUSEHOLD?
*NOTE: head of household **MUST** live in the household*

name ____

4 Head of household Gender

☐ 1= male
☐ 2= female

5 What is the **head of household's** relationship to the child (tick)

☐ 1= mother
☐ 2= father
☐ 3= step parent
☐ 4= grandparent
☐ 5= sibling
☐ 6= relative
☐ 7= OTHER: specify

Household Information

Observation of Dwelling (note: make on observation of the building materials of the home and record)

Observation of Dwelling

6 What is the major construction material of the external walls? code _
7 What is the major material of the roof? code _
8 What is the primary material of the floor? code _

6

Wall Material Codes	
1	Concrete
2	Tiles/shingles
3	Asbestos sheets
4	Metal sheets
5	Wood
6	Unbaked bricks
7	Thatch
8	Mud
9	Other: specify

7

Roof Material Codes	
1	Brick
2	Concrete
3	Unbarked brick, Adobe
4	Wood, Logs
5	Iron/Tin/Zinc sheeting
6	Mud
7	Bamboo
8	Canvas, Felt
9	Other:specify
10	Thatch

8

Floor Material Codes	
1	Parquet/linoleum
2	Painted wood
3	Tile
4	Concrete
5	Clay/earthen floor
6	Other:specify

9 Is the house is one of an extended compound (other family members in the compound)

☐ 0= NO
☐ 1= YES

10 Where does the **child's** biologic father live

☐ 1= **NOT** in the household
☐ 2= In the household
☐ 3= Father dead
☐ 99= Not Known

In the last **6 MONTHS**, how often has the child's biologic father seen him/her (the child)?

☐ 1= Daily
☐ 2= Weekly
☐ 3= Monthly
☐ 4= Less often than monthly
☐ 5= Never in the last 6 months
☐ 88= Father dead
☐ 99= Not Known

C. Child's Education

"Now I would like to ask some questions about your child's schooling, and whether your child has been able to go to school."

1 Has your child ever attended school? ☐ 0= NO ☐ 1= YES IF **NO** skip to Q3 and then SKIP REMAINING EDUCATION QUESTIONS

2 Is your child currently enrolled in school? ☐ 0= NO ☐ 1= YES **if yes, skip to Q4**

3 If your child has never attended or is not currently attending school, what are the main reasons? (○ & ☒)

note: CODED responses
If **Q1=NO, skip remaining section**

	1	Does not have assistive device
	2	Lack of money
	3	Child needs to work
	4	Education not very useful
	5	Being disabled was refused
	6	Don't like school
	7	Parent doesn't have enough time
	8	Family does not allow
	9	No transport
	10	Caregiver assumed disabled child could not attend
	11	Recent brief illness
	12	Other (specify):

☒ **(tick ANY** ○ **but CIRCLE most important)**

Please be sure that one answer choice above is **CIRCLED** to indicate the most important reason

4 Was your child allowed to start school at the time you wanted him or her to start? ☐ 0= NO ☐ 1= YES if **YES, skip Q5**

5 If **NO**, specify the main reason (using Q3's answer choices)
hint, use the answer choices from Q3 above to code this answer

	1	Does not have assistive device
	2	Lack of money
	3	Child needs to work
	4	Education not very useful
	5	Being disabled was refused
	6	Don't like school
	7	Parent doesn't have enough time
	8	Family does not allow
	9	No transport
	10	Caregiver assumed disabled child could not attend
	11	Recent brief illness
	12	Other (specify):

6 Has your child ever repeated a class at school? ☐ 0= NO ☐ 1= YES

7 If **YES,** how many classes has your child repeated? ☐☐

Child's Education

8 What is the highest level of education your child has completed

	1	Enrolled in Primary School (not yet completed)
	2	Primary (including kindergarten)
	3	Junior High
	4	Senior High
	5	Tertiary (include job training)
	99	No education

9 Was/Is your child's school a mainstream/regular school or special school?

	1	Mainstream
	2	Special school
	3	Mainstream with special unit

SKIP if child is not enrolled or has never been enrolled in school

10 In the last month of school, has your child missed some days? ☐ 0= NO ☐ 1= YES If NO, SKIP Remaining Question

11 If so, how many days did your child miss? _____ (number of days in missed in LAST MONTH)

12 Is this a typical number of days to miss? ☐ 0= NO ☐ 1= YES *hint: if parent can't remember, ask about the last week in order to ESTIMATE number of days per month missed*

13 What is the main reason your child missed these days in the last week of school?

	1	Does not have assistive device
	2	Lack of money
	3	Child needs to work
	4	Education not very useful
	5	Being disabled was refused
	6	Don't like school
	7	Parent doesn't have enough time
	8	Family does not allow
	9	No transport
	10	Caregiver assumed disabled child could not attend
	11	Recent brief illness
	12	Other (specify):

D. Cerebral Palsy Knowledge and Diagnosis

"Now I would like to ask you some questions about your child's condition."

note to interviewer: these responses are **CODED**, so choose the best response based on how the caregiver responds. Do not expect the caregiver to say *exactly* the same words as the coded answer.

1 What do you think is the cause of the difficulties your child faces? **&** **TICK AND CIRCLE**

CODED RESPONSES
(tick all that apply)
CIRCLE MAIN REASON

- 1 = Perinatal - A problem with/during/just after birth
- 2 = Trauma/injury **before** 2 years
- 3= Trauma/Injury **after** 2 years
- 4= Child's Illness **before** 2 years
- 5= Child's illness **after** 2 years
- 6= Mother's illness in pregnancy
- 7= Traditional belief (witchcraft, spirit child, curse, etc)
- 8= Other (specify)
- 9= Don't know

} *Specify what illness*

} *Specify what illness*

note: **please** be sure that at least one item **above** is ***CIRCLED*** , indicating the most significant cause according to the caregiver

2 How old was your child when you noticed something was wrong?

- 0= Noticed during pregnancy or just after birth
- 1= From 6 weeks of age until 1st birthday
- 2= From 1st birthday until 5th birthday
- 3= Noticed after 5th birthday
- 99= Don't know/refused

4 Where have you gone for a diagnosis or advice for your child's condition?
circle MAIN but tick ANY

CODED RESPONSES

- 1= village/community health worker or agent
- 2= hospital
- 3= pharmacy
- 4= mobile clinic
- 5= private doctor
- 6= health centre/post
- 7= traditional healer
- 99= DID NOT SEEK CARE → **SKIP Q5, Answer Q6**
- 8= other, specify

(tick all that apply)
CIRCLE ONE

go to Q6

note: **please** be sure that at least one item **above** is ***CIRCLED*** , indicating the primary place of care according to the caregiver

5 What information were you given about the condition?

6 IF you did **NOT** seek care for your child's condition, please specify the reason why you did **NOT SEEK CARE**
ONLY IF Q5=99

	Financial difficulties	**CODED RESPONSES**
	1 = I was refused at the [treatment center] because I had no money (or not enough)	
	2 = I had difficulty to get food for myself during my stay	**TICK UP TO THREE RESPONSES**
	3 = I didn't have money for treatment	
	4 = I didn't have money for medication/objects	

	Transport, access difficulties		**Difficulties at the health service**
	5 = there was no available transportation/it's very far away		11= I did not have the documents required to access health services
	6 = I had difficulty to find the money for transportation		12= there was no available medication
	7= No transport - public transit too difficulty, or refused travel on public transport		13= there was no service available for my need (condition)
	8= I had difficulty to find someone to go with me because nobody had time to take me		14= I was refused because my child is disabled
	9= I did not ask anybody because I felt that it was a waste of time		15= attitude of medical staff was negative
	10=I did not have an assistive device (wheelchair, etc)		16= The equipment that they gave is not very useful
			17= there is no female professional
			18 = no difficulty
			19 =other, specify _____

"These are questions about your understanding of your child's condition and health."

note: get out 5 item likert card

7 How would you describe your levels of knowledge about your child's condition?

- 0= No knowledge
- 1= A low level of knowledge
- 2= Some level of knowledge
- 3= A good level of knowledge
- 4= I feel I have lots of knowledge

8 How confident do you feel in how best to take care of your child?

- 0= No confidence
- 1= A low level of confidence
- 2= Some confidence
- 3= A good level of confidence
- 4= I feel I have lots of confidence

9 Have you heard of the condition called "cerebral palsy"?

- 0=NO
- 1=YES

Enter Child's ID number _ _

Ghana Cerebral Palsy Project 2015
Questionnaire for Primary Caregivers of Subjects

E. General Health Questions

note: These are questions about the **CHILD's** health

"Now I would like to ask some questions about your child's general health."

		Poor	Fair	Good	Very Good	Excellent	
1	In general, how would you describe your child's physical health?	0	1	2	3	4	
2	Most of the time, how do you think your child feels?	0	1	2	3	4	(ie, the way he or she feels about himself or herself and his or her life)

3 Has your child ever had a **seizure**, convulsion, or loss of consiousness? ☐ 0= NO ☐ 1= YES if **NO**, skip to **question 8**

4 Has your child had three or more seizures in the past year? ☐ 0= NO ☐ 1= YES

5 Number of seizures in the past year (tick one)
☐ 0= none ☐ 1= 1-2 seizures ☐ 2= 3-10 seizures ☐ 3= more than 10 ☐ 4= never had a seizure

6 Describe the usual type of seizure (CODED)
☐ 0= absence seizure type (staring spells - remains awake)
☐ 1= convulsions, limpness, complete loss of consciousness
☐ 2= other, or unable to describe/characterize
☐ 3= never had seizure

7 Has your child received the diagnosis of EPILEPSY from a healthcare worker (doctor, hospital, pharmacy, etc) ☐ 0= NO ☐ 1= YES

8 Has your child had any *serious* health problems in the last 12 months? ☐ 0= NO ☐ 1= YES **IF NO, SKIP to Q12**
(definition of serious: caregiver felt the child needed treatment)

9 If yes, what type of serious health event(s) or problem(s) did your child experience during this period? (Tick all that apply)

The responses are **CODED**, so choose the best response based on the caregiver's response

	Tick all that apply
	1. Severe diarrhea (with dehydration or > 14 days)
	2. Acute respiratory tract infection/pneumonia
	3. Malaria
	4. Eye infection/eye problem
	5. Ear infection/ear or hearing problem
	6. Malnutrition
	7. Vaccine-preventable disease (measles, chickenpox, mumps, rubella)
	8. Chronic Illness
	9. Accident/Injuries
	10. Don't know/ no information provided
	11. Other (specify)

10 Where did you seek advice or treatment? (tick **ALL** that apply)

go to Q11 ⇦

	1 Did not seek advice or treatment
	2 Village/community health worker or agent
	3 Hospital
	4 Pharmacy
	5 Mobile clinic
	6 Private doctor
	7 Health centre/post
	8 Traditional Healer
	9 Other (specify)

The responses are **CODED**, so choose the best response based on the caregiver's response

note: if the caregiver lists several, asks where they sought advice first
CIRCLE the most important

11. If you did not seek/receive advice or treatment, what was the reason? **Complete only if Q10=1**

(3 answers possible)

CODED RESPONSES

	Financial difficulties
	1 = I was refused at the [treatment center] because I had no money (or not enough)
	2 = I had difficulty to get food for myself during my stay
	3 = I didn't have money for treatment
	4 = I didn't have money for medication/objects
	Transport, access difficulties
	5 = there was no available transportation/it's very far away
	6 = I had difficulty to find the money for transportation
	7= No transport - public transit too difficulty, or refused travel on public transport
	8= I had difficulty to find someone to go with me because nobody had time to take me
	9= I did not ask anybody because I felt that it was a waste of time
	10=I did not have an assistive device (wheelchair, etc)
	Difficulties at the health service
	11= I did not have the documents required to access health services
	12= there was no available medication
	13= there was no service available for my need (condition)
	14= I was refused because my child is disabled
	15= attitude of medical staff was negative
	16= The equipment that they gave is not very useful
	17= there is no female professional
	18 = no difficulty
	19 =other, specify _____

"Thank you for answering those questions about the last year
These are a few questions about your child's health in just the past TWO weeks."

12 Has your child had diarrhea in the last two weeks? ☐ 0= NO ☐ 1= YES

13 Has your child been ill with fever at any time in the last two weeks? ☐ 0= NO ☐ 1= YES

14 Has your child had an illness with a cough at any time in the last two weeks? ☐ 0= NO ☐ 1= YES

15 Has your child had fast, short, rapid breaths or difficulty breathing at any time in the last 2 weeks? ☐ 0= NO ☐ 1= YES

F. **Eating and Drinking**

"I would now like to ask you about how your child eats and drinks, and what that is like for you."

			Never	Almost Never	Sometimes	Often	Always
1	How often does your child have problems with eating and drinking? *(ie: do meals take a long time, does the child get upset during meals, do you have to force your child to eat?)*		0	1	2	3	4
2	How often is it a problem that your child does NOT eat the same food as other children the same age?		0	1	2	3	4
3	How often is it a problem that your child coughs or chokes while eating or drinking?		0	1	2	3	4
4	How often does your child have problems wtih feeding himself/herself?		0	1	2	3	4
5	How often does your child need help with feeding?		0	1	2	3	4
6	How often is it a problem that your child is unhappy during mealtimes?		0	1	2	3	4
7	How often is it a problem that your child is NOT eating enough?		0	1	2	3	4
8	How often do you worry about these problems?		0	1	2	3	4

9 Compared to other children about the same age as (name), how long to typical meals require?

- ☐ 1= faster than other child of the same age
- ☐ 2= the same as other children the same age
- ☐ 3= somewhat longer than other children the same age
- ☐ 4= (more than 1 hour) much longer than other children the same age

10 Is your child growing and putting on weight like other children?

- ☐ 0= NO
- ☐ 1= YES

11 If not, what do you believe is the reason your child is not growing and putting on weight like other children?

M. Anthropometry - measurements

"I now need to take measurements of your child to see how they are growing."
"If you have questions during the measurements about your child, please ask me."

note: ask the parent to remove the child's shoes, heavy clothes, and any hair fixtures (ribbons, bows)
note: Record all measurements to the nearest 1 decimal (eg: 54.1)
note: all measurements in centimeters must be completed by both examiners and have a difference of 0.5cm or LESS
REPEAT AS NEEDED until measurements agree
all children will have a measurement of height, weight, head circumference, mid upper arm circumference, and GMFCS

note: both standing height and knee height will use the level, tape measure, and flat piece
recumbant length will use the tape measure and flat piece

these are the guidelines for each child depending on their age

age 0-4 years	**age 5-18 years**
height: recumbant length	height: standing height or seated knee height
knee height	knee height
tibial length	tibial length
weight: standing alone or	weight: standing alone or
held by parent	held by parent or examiner
head circumference	head circumference
MUAC & GMFCS	MUAC & GMFCS

HEIGHT

LAYING LENGTH (XX.X cm)
for age 0-4 years

1st examiner _____ cm 2nd examiner _____ cm
agreement of 0.5cm or less?

STANDING HEIGHT - if possible XX.X cm
age 5-18 years

1st examiner _____ cm 2nd _____ cm
agreement of 0.5cm or less?

seated knee height (XX.Xcm)

1st examiner _____ cm 2nd _____ cm
agreement of 0.5cm or less?

tibial length (XX.Xcm)

1st examiner _____ cm 2nd _____ cm
agreement of 0.5cm or less?

WEIGHT XX.Xkg

standing weight (if child can stand without support)

OR, weigh holding child _____ kg

weight of parent _____ kg

total weight while parent holding child _____ kg

HEAD CIRCUMFERENCE

head circ 1st examiner _____(XX.Xcm)
head circ 2nd examiner _____
agreement of 0.5cm or less?

MUAC *left* arm _____ (XXX mm)
right arm _____(only if problems with left)

GMFCS

please refer to the age appropriate GMFCS page and assess the child's GMFCS classification level.

you may ask the parent questions and examen the child in order to make this assessment

GMFCS Level
I
II
III
IV
V

make note of any difficulties with any of these measurements

K. PEDS QL Family Impact Module

DIRECTIONS/Adekyerɛ

Families of children sometimes have special concerns or difficulties because of the child's health. On the following page is a list of things that might be a problem for **you**. Please tell us **how much of a problem** each one has been for **you** during the **past ONE month** by circling:

Ɛtɔ dabi a, abusuafo a wɔmowɔ nkora, wɔ nsɛm anara ɔhaw ɛfa abofra ne yareɛ ho. Krataa yi so kyerɛ **nsɛm a abia ɛhawo**. Mepawokyew, **kyerɛ sɛdia nsɛm** no **ahawo bosome bako** emu. Kyerɛ dia ɛfa woho.

0 if it is **never** a problem	0	sɛ ɛnnyɛ ɔhaw
1 if it is **almost never** a problem	1	sɛ ɛnntaa ɛnnyɛ ɔhaw
2 if it is **sometimes** a problem	2	sɛ ɛyɛ ɔhaw kakra
3 if it is **often** a problem	3	sɛ ɛtaa yɛ ɔhaw
4 if it is **almost always** a problem	4	sɛ dabiara ɛyɛ ɔhaw

There are no right or wrong answers.

If you do not understand a question, please ask for help.

Physical Functioning *Nsɛm a ɛha nipadua ….*

In the past **ONE month**, as a result of your child's health, how much of a problem have **you** had with...

Bosome bako a etwa mu yi, ɛfa woba n'eyareɛ ho, sɛn na nsɛm a edi so yi ho aha **wo** ……

	never	almost never	sometimes	often	almost always
1. I feel tired during the day	0	1	2	3	4
2. I feel tired when I wake up in the morning	0	1	2	3	4
3. I feel too tired to do the things I like to do	0	1	2	3	4
4. I get headaches	0	1	2	3	4
5. I feel physically weak	0	1	2	3	4
6. I feel sick to my stomach	0	1	2	3	4

Emotional Functioning

In the past **ONE month**, as a result of your child's health, how much of a problem have **you** had with...

	never	almost never	sometimes	often	almost always
1. I feel anxious	0	1	2	3	4
2. I feel sad	0	1	2	3	4
3. I feel angry	0	1	2	3	4
4. I feel frustrated	0	1	2	3	4
5. I feel helpless or hopeless	0	1	2	3	4

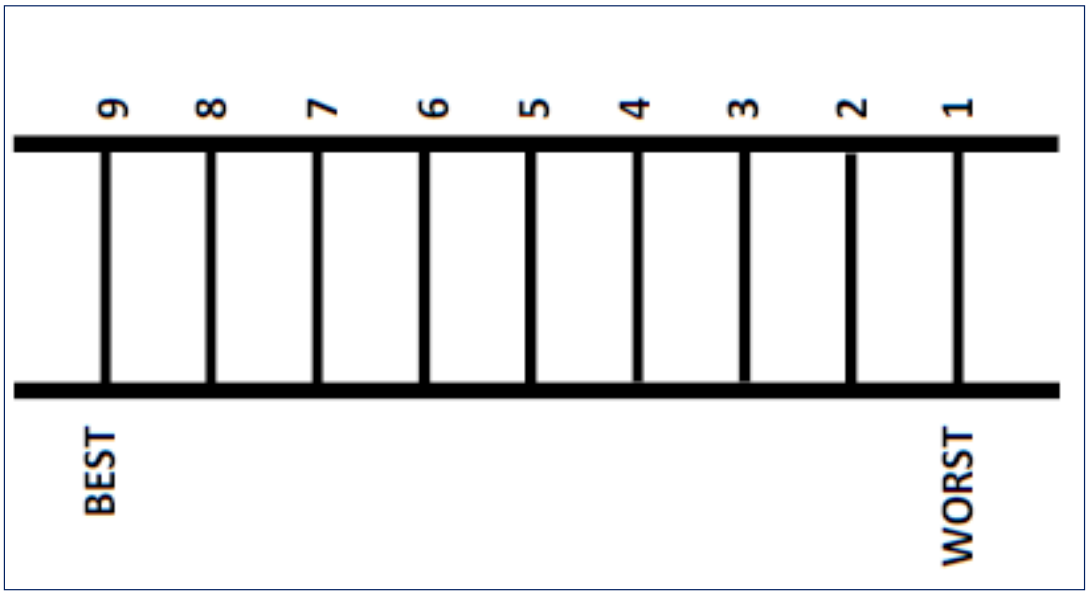
Social Functioning

In the past **ONE month**, as a result of your child's health, how much of a problem have **you** had with...

	never	almost never	sometimes	often	almost always
1. I feel isolated from others	0	1	2	3	4
2. I have trouble getting support from others	0	1	2	3	4
3. It is hard to find time for social activities	0	1	2	3	4
4. I do not have enough energy for social activities	0	1	2	3	4

I. Rehabilitation

	"I am now going to ask you some questions about some services specifically for people with disabilities that you may or may not have heard of or have used now or in the past"	1.1 Have you ever heard of this type of service?	1.2 Has your child ever needed this service?	1.3 Has your child ever recieved this service?	1.4 If yes, is your child currently recieving or using it?	1.5 If reported needing (Yes to Q1.2) but not receiving a service (No to Q1.3), ask why has your child not recieved it?	1.6 If reported once receiving/using service (Yes to Q1.3) but not receiving it now (No to Q1.4), ask why is your child no longer recieving it?
		0= No → Skip to NEXT SERVICE 1= Yes →	0= No → Skip to NEXT SERVICE 1= Yes →	0 = No → Q1.5 1 = Yes → Q1.4	0 = No → Q1.6 **1 = Yes →** Skip to NEXT SERVICE	1 = Too expensive 2 = Too far/no transport 3 = Discriminating 4 = Communication bariers 5 = Don't know where to access 6 = Service not available 7= Other (specify)_____ **up to three responses allowed**	1 = Too expensive 2 = Too far/no transport 3 = Not longer available 4 = Communication/language barriers 5 = Don't know where to access 6 = Not really helping me 7 = Not satisfied with services 8= No longer need the service 9=Broken and unable to repair 10=other (specify) **up to three responses allowed**
1	**Medical rehabilitation** (e.g. physiotherapy, occupational therapy, speech and hearing therapy etc)	0 1	0 1	0 1	0 1		
2	**Assistive devices service** (e.g. standing frames, special chair, Sign language interpreter, wheelchair, hearing/visual aids, Braille etc.)	0 1	0 1	0 1	0 1		
7	**Disability Fund** (government assistance)	0 1	0 1	0 1	0 1		



YOUNG LIVES LADDER

Appendix 9: Endline survey questionnaire

Enter Child's ID number _ _

Ghana Cerebral Palsy Project 2015
Questionnaire for Primary Caregivers of Subjects

A. Demographics

3 District (tick)			
1=	Agogo CP	6=	Dormaa
2=	Bawku CP	7=	Duayaw Nkwanta
3=	Bolga CP	8=	Garu-Tempane
4=	Langbensi	9=	Sirigu
5=	Dodowa		

4 Group Name (tick)			
1=	PHC & Physio Unit Agogo	6=	PHC & Physio Unit Dorma
2=	Bawku Physio unit	7=	Physio Unit Duayaw Nkwanta
3=	PHC Bolga	8=	Garu
4=	Presby HC Langbensi	9=	Afrikids (Sirigu)
5=	Dodowa		

Left in these sites for now as wanted to check whether you wanted numbered codes for subsequent sites to stay the same or char

B. Childs Information

5 Child's Study ID Number [ ][ ] is this OK or does it have to be separate Qs for cases and
for controls write ID number of the matched child

? 6 **Child's** Name _____ 7 What is the **CHILD's** age (in years) [ ][ ]

8 What is the **CHILD's** gender? [ ] 1= male [ ] 2= female

Record **CHILD's** date of birth __ / __ / __
day/ mo/ year

Note to interviewer: these questions below are about the **CAREGIVER** for the child

9a We conducted an interview about X (child's name) last year. Can we confirm that we conducted this with you?

	Person interviewed	*Action for cases*	what does this mean?
[ ] 1=	Same caregiver as baseline	*Continue with caregiver questions*	
2=	Different primary caregiver (state reason)	*Continue with caregiver questions*	
3=	No primary caregiver available	*Do not ask caregiver questions*	

9.b If 3(different primary caregiver) then check:

[ ] 1= Primary caregiver has moved/died
2= Primary caregiver not available today
3= Other (specify) [ ]

Enter Child's ID number _ _ Ghana Cerebral Palsy Project 2015
Questionnaire for Primary Caregivers of Subjects

C. Child's Education- for children of 3 or 4 years and upwards?

"Now I would like to ask some questions about your child's schooling, and whether your child has been able to go to school since we last spoke"

1 Is your child currently enrolled in school? ☐ 0= NO ☐ 1= YES **if yes, skip to Q2**

2 Has your child been NEWLY enrolled in school in the last year since the start of the training,
0= NO
1= YES Go to Q3 if YES

3 If yes What is the main reason your child has enrolled in the last year Go to Q4 if No

1= Child has now reached the correct age for enrollment
2= Transport has been provided
3= The school has accepted the child ☒ **(tick ANY but CIRCLE most important)**
4= The family now allows the child to attend
5= Caregiver understands the child is capable of attending school
6= The child is now healthy enough to attend school
7= The child has an assistive device to support access
8= Other

If yes to child has received support please provide summary detail of key support provided

SKIP if child is not enrolled or has never been enrolled in school

For all children enrolled on school

4 In the last month of school, has your child missed some days?
☐ 0= NO If NO, SKIP Remaining Question
☐ 1= YES

5 If so, how many days did your child miss? _____
(number of days in missed in LAST MONTH)

6 Is this a typical number of days to miss?
☐ 0= NO
☐ 1= YES
hint: if parent can't remember, ask about the last week in order to ESTIMATE number of days per month missed

7 What is the main reason your child missed these days in the last week of school?

Enter Child's ID number _ _

Ghana Cerebral Palsy Project 2015
Questionnaire for Primary Caregivers of Subjects

D. Cerebral Palsy Knowledge and Diagnosis

"Now I would like to ask you some questions about your child's condition."

note to interviewer: these responses are **CODED**, so choose the best response based on how the caregiver responds. Do not expect the caregiver to say *exactly* the same words as the coded answer.

1 What do you think is the cause of the difficulties your child faces? & **TICK AND CIRCLE**

CODED RESPONSES

(tick all that apply)

CIRCLE MAIN REASON

- ☐ 1 = Perinatal - A problem with/during/just after birth
- ☐ 2 = Trauma/injury **before** 2 years
- ☐ 3= Trauma/Injury **after** 2 years
- ☐ 4= Child's Illness **before** 2 years } *Specify what illness* ____
- ☐ 5= Child's illness **after** 2 years
- ☐ 6= Mother's illness in pregnancy } *Specify what illness* ____
- ☐ 7= Traditional belief (witchcraft, spirit child, curse, etc)
- ☐ 8= Other (specify) ____
- ☐ 9= Don't know
- ☐ 10=problem to the brain/cerebral palsy

does the parent have to use the words "cerebral palsy"? Som

note: **please** be sure that at least one item **above** is ***CIRCLED*** , indicating the most significant cause according to the caregiver

"These are questions about your understanding of your child's condition and health."

note: get out 5 item likert card

2 How would you describe your levels of knowledge about your child's condition?

- ☐ 0= No knowledge
- ☐ 1= A low level of knowledge
- ☐ 2= Some level of knowledge
- ☐ 3= A good level of knowledge
- ☐ 4= I feel I have lots of knowledge

renumbered

show a response scale - ladder

3 How confident do you feel in how best to take care of your child?

- ☐ 0= No confidence
- ☐ 1= A low level of confidence
- ☐ 2= Some confidence
- ☐ 3= A good level of confidence
- ☐ 4= I feel I have lots of confidence

show a response scale -ladder

4 Have you heard of the condition called "cerebral palsy"?

- ☐ 0=NO
- ☐ 1=YES

Enter Child's ID number _ _

Ghana Cerebral Palsy Project 2015
Questionnaire for Primary Caregivers of Subjects

E. General Health Questions

note: These are questions about the **CHILD's** health

"Now I would like to ask some questions about your child's general health."

		Poor	Fair	Good	Very Good	Excellent	
1	In general, how would you describe your child's physical health?	0	1	2	3	4	
2	Most of the time, how do you think your child feels?	0	1	2	3	4	(ie, the way he or she feels about himself or herself and his or her life)

3 Has your child received the diagnosis of EPILEPSY from a healthcare worker (doctor, hospital, pharmacy, etc) ☐ 0= NO ☐ 1= YES

4 Has your child ever received mediaction for epilepsy? ☐ 0= NO

5 Is your son/daughter receiving medication currently for treatment of epilepsy yes/no **(Only ask If diagnosis = YES** ☐ 1= YES

6 If no what are the main reasons for your child not to be take medication?

1= ☐ Lack of financial resources to pay for drugs
2= ☐ Drugs have run out at home
3= ☐ Drugs are not available at the local clinic
4= ☐ I do not think the medication helps
5= ☐ Other

Ask the Q but not the list of responses - tick whichever one matches b

8 Has your child had any *serious* health problems in the last 12 months? ☐ 0= NO **IF NO, SKIP to Q12**
(definition of serious: caregiver felt the child needed treatment) ☐ 1= YES

9 If yes, what type of serious health event(s) or problem(s) did your child experience during this period? (Tick all that apply)

The responses are **CODED**, so choose the best response based on the caregiver's response

ask question but then no further probes

Tick all that apply
☐ 1. Severe diarrhea (with dehydration or > 14 days)
☐ 2. Acute respiratory tract infection/pneumonia
☐ 3. Malaria
☐ 4. Eye infection/eye problem
☐ 5. Ear infection/ear or hearing problem
☐ 6. Malnutrition
☐ 7. Vaccine-preventable disease (measles, chickenpox, mumps, rubella)
☐ 8. Chronic Illness
☐ 9. Accident/Injuries
☐ 10. Don't know/ no information provided
☐ 11. Other (specify)

10 Where did you seek advice or treatment? (tick **ALL** that apply)

go to Q11 ⇦

☐	1 Did not seek advice or treatment
☐	2 Village/community health worker or agent
☐	3 Hospital
☐	4 Pharmacy
☐	5 Mobile clinic
☐	6 Private doctor
☐	7 Health centre/post
☐	8 Traditional Healer
☐	9 Other (specify)
☐	10 Nutritionist

The responses are **CODED**, so choose the best response based on the caregiver's response

note: if the caregiver lists several, asks where they sought advice first

CIRCLE the most important

11. If you did not seek/receive advice or treatment, what was the reason? **Complete only if Q10=1**

(3 answers possible)

CODED RESPONSES

	Financial difficulties
	1 = I was refused at the [treatment center] because I had no money (or not enough)
	2 = I had difficulty to get food for myself during my stay
	3 = I didn't have money for treatment
	4 = I didn't have money for medication/objects
	Transport, access difficulties
	5 = there was no available transportation/it's very far away
	6 = I had difficulty to find the money for transportation
	7= No transport - public transit too difficulty, or refused travel on public transport
	8= I had difficulty to find someone to go with me because nobody had time to take me
	9= I did not ask anybody because I felt that it was a waste of time
	10=I did not have an assistive device (wheelchair, etc)
	Difficulties at the health service
	11= I did not have the documents required to access health services
	12= there was no available medication
	13= there was no service available for my need (condition)
	14= I was refused because my child is disabled
	15= attitude of medical staff was negative
	16= The equipment that they gave is not very useful
	17= there is no female professional
	18 = no difficulty
	19 =other, specify _____

"Thank you for answering those questions about the last year
These are a few questions about your child's health in just the past TWO weeks." from DHSS survey in Ghana

12 Has your child had diarrhea in the last two weeks? ☐ 0= NO ☐ 1= YES

13 Has your child been ill with fever at any time in the last two weeks? ☐ 0= NO ☐ 1= YES

14 Has your child had an illness with a cough at any time in the last two weeks? ☐ 0= NO ☐ 1= YES

15 Has your child had fast, short, rapid breaths or difficulty breathing at any time in the last 2 weeks? ☐ 0= NO ☐ 1= YES

F. **Eating and Drinking**

"I would now like to ask you about how your child eats and drinks, and what that is like for you."

			Never	Almost Never	Sometimes	Often	Always
1	How often does your child have problems with eating and drinking? *(ie: do meals take a long time, does the child get upset during meals, do you have to force your child to eat?)*		0	1	2	3	4
2	How often is it a problem that your child does NOT eat the same food as other children the same age?		0	1	2	3	4
3	How often is it a problem that your child coughs or chokes while eating or drinking?		0	1	2	3	4
4	How often does your child have problems wtih feeding himself/herself?		0	1	2	3	4
5	How often does your child need help with feeding?		0	1	2	3	4
6	How often is it a problem that your child is unhappy during mealtimes?		0	1	2	3	4
7	How often is it a problem that your child is NOT eating enough?		0	1	2	3	4
8	How often do you worry about these problems?		0	1	2	3	4

9 Compared to other children about the same age as (name), how long do typical meals require?

- ☐ 1= faster than other child of the same age
- ☐ 2= the same as other children the same age
- ☐ 3= somewhat longer than other children the same age
- ☐ 4= (more than 1 hour) much longer than other children the same age

10 Is your child growing and putting on weight like other children?

- ☐ 0= NO
- ☐ 1= YES

11 If not, what do you believe is the reason your child is not growing and putting on weight like other children?

12. How confident do you feel now about feeding your child? (tick one answer)

- ☐ 0 = No confidence
- 1 = A low level of confidence
- 2 = Some level of confidence
- 3 = A good level of confidence
- 4 = I feel I have lots of confidence

13. Has your child been referred to see a nutritionist?
0 = IF NO, SKIP TO Q21
1 = YES

these are the new Qs from Jackie

14. Did your child see the nutritionist?

0 = IF NO, SKIP TO Q19
1 = YES

15. Where did your child see the nutritionist? Tick all that apply

- [ ] 1. At the hospital
- [ ] 2. At a local community clinic
- [ ] 3. The nutritionist comes to the house
- [ ] 4. Other (specify)

16. Have you stopped seeing the nutritionist? (Complete only if Q14=1)

- [ ] 0 = IF NO, GO TO Q21
- [ ] 1 = YES

17. If yes, what was the reason that you stopped seeing the nutritionist? (Ask as an open question, interviewer to code accordingly)

Financial difficulties

- [ ] 1 = I was refused at the [treatment center] because I had no money (or not enough)
- [ ] 2 = I had difficulty to get food for myself during my stay
- [ ] 3 = I didn't have money for treatment
- [ ] 4 = I didn't have money for medication/objects

Tick up to 3 responses

Transport, access difficulties

- [ ] 5 = there was no available transportation/it's very far away
- [ ] 6 = I had difficulty to find the money for transportation
- [ ] 7= Public transport too difficulty, or refused travel on public transport
- [ ] 8= I had difficulty to find someone to go with me because nobody had time to take me
- [ ] 9= I did not ask anybody because I felt that it was a waste of time
- [ ] 10= I did not have an assistive device to help me with transport (wheelchair, etc)

Difficulties at the health service

- [ ] 11= I did not have the documents required to access health services
- [ ] 12= there was no service available for my need (condition)
- [ ] 13= I was refused because my child is disabled
- [ ] 14= attitude of medical staff was negative
- [ ] 15= The food that they gave is not very useful
- [ ] 16= The advice that they gave is not very useful
- [ ] 17 = no difficulty
- [ ] 18 =other, specify

Child health

- [ ] 19= My child's health did not get better
- [ ] 20= My child is better

18. Out of your 3 responses, which one do you feel is the most important? (Write the associated code and answer)

[ ]

19. If you did not see the nutritionist, what was the reason (Complete only if Q14=0)

Tick the 3 main reasons

Financial difficulties

- [ ] 1 = I was refused at the [treatment center] because I had no money (or not enough)
- [ ] 2 = I had difficulty to get food for myself during my stay
- [ ] 3 = I didn't have money for treatment
- [ ] 4 = I didn't have money for medication/objects

3 possible main reasons

Circle the most important

Transport, access difficulties

- [ ] 5 = there was no available transportation/it's very far away
- [ ] 6 = I had difficulty to find the money for transportation
- [ ] 7= Public transport too difficulty, or refused travel on public transport
- [ ] 8= I had difficulty to find someone to go with me because nobody had time to take me
- [ ] 9= I did not ask anybody because I felt that it was a waste of time

☐ 10= I did not have an assistive device to help me with transport (wheelchair, etc)

Difficulties at the health service

☐ 11= I did not have the documents required to access health services
☐ 12= there was no service available for my need (condition)
☐ 13= I was refused because my child is disabled
☐ 14= attitude of medical staff was negative
☐ 15= The food that they gave is not very useful
☐ 16= The advice that they gave is not very useful
☐ 17 = no difficulty
☐ 18 =other, specify

20. Out of your 3 responses, which one do you feel is the most important? (Write the associated code and answer)

21. Do you think that your child needs to see a nutritionist? (ask all participants)

☐ 0 = NO
☐ 1 = YES

22. What is the reason for your answer? (all participants to answer why they responded yes or no)

23. Has your child admitted to hospital for malnutrition within the last 12 months? amend and tell Jackie

☐ 0 = NO
☐ 1 = YES

24. How many times has your child been admitted in the last year? (Complete only if Q23=1)

Number of times = ☐

25. For each time your child was admitted to hospital, how many days did they stay in the hospital? (Complete only if Q23=1)

☐ eg. Admission 1= 2 days, Admission 2 = 10 days

13. Has your child been referred to see a nutritionist?

0 = IF NO, SKIP TO Q24 these are the new Qs from Jackie
1 = YES

14. Did your child see the nutritionist?

0 = IF NO, SKIP TO Q16
1 = YES

15. Tick all that apply

1. At the hospital
2. At a local community clinic
3. The nutritionist comes to the house
4. Other (specify)

16. If you did not see the nutritionist, what was the reason Complete only if Q13=0

Financial difficulties

☐ 1 = I was refused at the [treatment center] because I had no money (or not enough) 3 possible main reasons
☐ 2 = I had difficulty to get food for myself during my stay
☐ 3 = I didn't have money for treatment ? Circle the most important
☐ 4 = I didn't have money for medication/objects

Transport, access difficulties
- [ ] 5 = there was no available transportation/it's very far away
- [ ] 6 = I had difficulty to find the money for transportation
- [ ] 7= No transport - public transit too difficulty, or refused travel on public transport
- [ ] 9= I did not ask anybody because I felt that it was a waste of time
- [ ] 10= I did not have an assistive device (wheelchair, etc)

Difficulties at the health service
- [ ] 11= I did not have the documents required to access health services
- [ ] 12= there was no available medication
- [ ] 13= there was no service available for my need (condition)
- [ ] 14= I was refused because my child is disabled
- [ ] 15= attitude of medical staff was negative
- [ ] 16= The equipment that they gave is not very useful
- [ ] 17= there is no female professional
- [ ] 18 = no difficulty
- [ ] 19 =other, specify

20. Have you stopped seeing the nutritionist? (Complete only if Q17=1)

- [ ] 0 = IF NO, GO TO Q22
- [ ] 1 = YES

21. If yes, what were the main reasons that you stopped seeing the nutritionist?

(3 ¿Financial difficulties Tick 3 main reasons
- [ ] 1 = I was refused at the [treatment center] because I had no money (or not enough)
- [ ] 2 = I had difficulty to get food for myself during my stay

CODED
- [ ] 3 = I didn't have money for treatment
- [ ] 4 = I didn't have money for medication/objects

Transport, access difficulties
- [ ] 5 = There was no available transportation/it's very far away
- [ ] 6 = I had difficulty to find the money for transportation
- [ ] 7= No transport - public transit too difficulty, or refused travel on public transport
- [ ] 9= I did not ask anybody because I felt that it was a waste of time
- [ ] 10= I did not have an assistive device (wheelchair, etc)

Difficulties at the health service
- [ ] 11= I did not have the documents required to access health services
- [ ] 12= There was no available medication
- [ ] 13= There was no service available for my need (condition)
- [ ] 14= I was refused because my child is disabled
- [ ] 15= Attitude of medical staff was negative
- [ ] 16= The equipment that they gave is not very useful
- [ ] 17= There is no female professional
- [ ] 18 = No difficulty
- [ ] 19 = Other, specify

Child health
- [ ] 20=My child's health did not get better
- [ ] 21= My child is better

M. Anthropometry - measurements any of these that we shouldn't repeat? Do we repat the GMFC?

"I now need to take measurements of your child to see how they are growing."

"If you have questions during the measurements about your child, please ask me."

note: ask the parent to remove the child's shoes, heavy clothes, and any hair fixtures (ribbons, bows)
note: Record all measurements to the nearest 1 decimal (eg: 54.1)
note: all measurements in centimeters must be completed by both examiners and have a difference of 0.5cm or LESS
REPEAT AS NEEDED until measurements agree
all children will have a measurement of height, weight, head circumference, mid upper arm circumference, and GMFCS

note: both standing height and knee height will use the level, tape measure, and flat piece
recumbant length will use the tape measure and flat piece

these are the guidelines for each child depending on their age

☐ **age 0-4 years**
- ☐ height: recumbant length
- ☐ knee height
- ☐ tibial length
- ☐ weight: standing alone or
- ☐ held by parent
- ☐ head circumference
- ☐ MUAC & GMFCS

☐ **age 5-18 years**
- ☐ height: standing height or seated knee height
- ☐ knee height
- ☐ tibial length
- ☐ weight: standing alone or
- ☐ held by parent or examiner
- ☐ head circumference
- ☐ MUAC & GMFCS

just for children
check with David how

HEIGHT

LAYING LENGTH (XX.X cm)
for age 0-4 years

1st examiner _____ cm 2nd examiner _____ cm
☐ agreement of 0.5cm or less?

STANDING HEIGHT - if possible XX.X cm
age 5-18 years

1st examiner _____ cm 2nd _____ cm
☐ agreement of 0.5cm or less?

seated knee height (XX.Xcm)

1st examiner _____ cm 2nd _____ cm
☐ agreement of 0.5cm or less?

tibial length (XX.Xcm)

1st examiner _____ cm 2nd _____ cm
☐ agreement of 0.5cm or less?

WEIGHT XX.Xkg

standing weight (if child can stand without support)

OR, weigh holding child _____ kg

weight of parent _____ kg

total weight while parent holding child _____ kg

HEAD CIRCUMFERENCE

head circ 1st examiner _____(XX.Xcm)
head circ 2nd examiner _____
☐ agreement of 0.5cm or less?

MUAC *left* arm _____ (XXX mm)
right arm _____(only if problems with left)

K. PEDS QL Family Impact Module

Families of children sometimes have special concerns or difficulties because of the child's health. On the following page is a list of things that might be a problem for **you**. Please tell us **how much of a problem** each one has been for **you** during the **past ONE month** by circling:

Ɛtɔ dabi a, abusuafo a wɔmowɔ nkora, wɔ nsɛm anara ɔhaw ɛfa abofra ne yareɛ ho. Krataa yi so kyerɛ **nsɛm a abia ɛhawo**. Mepawokyew, **kyerɛ sɛdia nsɛm** no **ahawo bosome bako** emu. Kyerɛ dia ɛfa woho.

0 if it is **never** a problem	0	sɛ ɛnnyɛ ɔhaw
1 if it is **almost never** a problem	1	sɛ ɛnntaa ɛnnyɛ ɔhaw
2 if it is **sometimes** a problem	2	sɛ ɛyɛ ɔhaw kakra
3 if it is **often** a problem	3	sɛ ɛtaa yɛ ɔhaw
4 if it is **almost always** a problem	4	sɛ dabiara ɛyɛ ɔhaw

There are no right or wrong answers.

If you do not understand a question, please ask for help.

Physical Functioning *Nsɛm a ɛha nipadua ….*

In the past **ONE month**, as a result of your child's health, how much of a problem have **you** had with...

Bosome bako a etwa mu yi, ɛfa woba n'eyareɛ ho, sɛn na nsɛm a edi so yi ho aha **wo** ……

	never	almost never	sometimes	often	almost always
1. I feel tired during the day	0	1	2	3	4
2. I feel tired when I wake up in the morning	0	1	2	3	4
3. I feel too tired to do the things I like to do	0	1	2	3	4
4. I get headaches	0	1	2	3	4
5. I feel physically weak	0	1	2	3	4
6. I feel sick to my stomach	0	1	2	3	4
Emotional Functioning In the past **ONE month**, as a result of your child's health, how much of a problem have **you** had with...	never	almost never	sometimes	often	almost always
1. I feel anxious	0	1	2	3	4
2. I feel sad	0	1	2	3	4
3. I feel angry	0	1	2	3	4
4. I feel frustrated	0	1	2	3	4
5. I feel helpless or hopeless	0	1	2	3	4
Social Functioning In the past **ONE month**, as a result of your child's health, how much of a problem have **you** had with...	never	almost never	sometimes	often	almost always
1. I feel isolated from others	0	1	2	3	4
2. I have trouble getting support from others	0	1	2	3	4
3. It is hard to find time for social activities	0	1	2	3	4
4. I do not have enough energy for social activities	0	1	2	3	4

Enter Child's ID number _ _

Ghana Cerebral Palsy Project 2015
Questionnaire for Primary Caregivers of Subjects

Cognitive Functioning In the past **ONE month**, as a result of your child's health, how much of a problem have **you** had with...	never	almost never	sometimes	often	almost always
1. It is hard for me to keep my attention on things	0	1	2	3	4
2. It is hard for me to remember what people tell me	0	1	2	3	4
3. It is hard for me to remember what I just heard	0	1	2	3	4
4. It is hard for me to think quickly	0	1	2	3	4
5. It is hard for me to remember what I was just thinking	0	1	2	3	4

Communication Functioning In the past **ONE month**, as a result of your child's health, how much of a problem have **you** had with...	never	almost never	sometimes	often	almost always
1. I feel that others do not understand my family's situation	0	1	2	3	4
2. It is hard for me to talk about my child's health with others	0	1	2	3	4
3. It is hard for me to tell doctors and nurses how I feel	0	1	2	3	4

Worry In the past **ONE month**, as a result of your child's health, how much of a problem have **you** had with...	never	almost never	sometimes	often	almost always
1. I worry about whether or not my child's medical treatments are working	0	1	2	3	4
2. I worry about the side effects of my child's medications/medical treatments	0	1	2	3	4
3. I worry about how others will react to my child's condition	0	1	2	3	4
4. I worry about how my child's illness is affecting other family members	0	1	2	3	4
5. I worry about my child's future	0	1	2	3	4

Next is a list of things that might be a problem for **your family**. Please tell us **how much of a problem** each one has been for **your family** during the **past ONE month.**

Daily Activities In the past **ONE month**, as a result of your child's health, how much of a problem has **your family** had with...	never	almost never	sometimes	often	almost always
1. Family activities taking more time and effort	0	1	2	3	4
2. Difficulty finding time to finish household tasks	0	1	2	3	4
3. Feeling too tired to finish household tasks	0	1	2	3	4

Family Relationships In the past **ONE month**, as a result of your child's health, how much of a problem has **your family** had with...	never	almost never	sometimes	often	almost always
1. Lack of communication between family members	0	1	2	3	4
2. Conflicts between family members	0	1	2	3	4
3. Difficulty making decisions together as a family	0	1	2	3	4
4. Difficulty solving family problems together	0	1	2	3	4
5. Stress or tension between family members	0	1	2	3	4

I. Rehabilitation

There needs to be a very clear question about the health insurance card -- I think - Check when they received it - if they receuve as RESULT OF THE INTERVENTION? (quite time consuming?)

	"I am now going to ask you some questions about some services specifically for people with disabilities that you may or may not have heard of or have used now or in the past"	1.1 Have you ever heard of this type of service?	1.2 Has your child ever needed this service?	1.3 Has your child ever recieved this service?	1.4 If yes, is your child currently recieving or using it?	1.5 If reported needing (Yes to Q1.2) but not receiving a service (No to Q1.3), ask why has your child not recieved it?	1.6 If reported once receiving/using service (Yes to Q1.3) but not receiving it now (No to Q1.4), ask why is your child no longer recieving it?
		0= No → Skip to NEXT SERVICE 1= Yes →	0= No → Skip to NEXT SERVICE 1= Yes →	0 = No → Q1.5 1 = Yes → Q1.4	0 = No → Q1.6 **1 = Yes** → Skip to NEXT SERVICE	1 = Too expensive 2 = Too far/no transport 3 = Discriminating 4 = Communication bariers 5 = Don't know where to access 6 = Service not available 7= Other (specify)_____ **up to three responses allowed**	1 = Too expensive 2 = Too far/no transport 3 = Not longer available 4 = Communication/language barriers 5 = Don't know where to access 6 = Not really helping me 7 = Not satisfied with services 8= No longer need the service 9=Broken and unable to repair 10=other (specify) **up to three responses allowed**
1	**Medical rehabilitation** (e.g. physiotherapy, occupational therapy, speech and hearing therapy etc)	0 1	0 1	0 1	0 1		
2	**Assistive devices service** (e.g. standing frames, special chair, Sign language interpreter, wheelchair, hearing/visual aids, Braille etc.)	0 1	0 1	0 1	0 1		
3	**Disability Fund** (government assistance)	0 1	0 1	0 1	0 1		

4 Health Insurance Card

Request to see the HIC - current and/or old card

4. 1 Do you have a current up to date HIC for child X [ ] 0= NO 1= YES

If YES:

4 HIC card observed by the researcher [ ] 0= NO 1= YES

4 Date of card renewal [ ] [ ] [ ]

4 Did the training project facilitate obtaining this new HIC card [ ] 0= NO 1= YES

5 Date old HIC card expired [ ] date [ ]

[ ] if available [ ] not available

REHABILITATION QUESTIONS

"I'm now going to some questions about assistive devices and your child" ? Add in hint with description of assistive devices

Q.1 Does your child have any assistive devices? ? By assistive devices we mean ….
Yes / No If yes > Q.2 If no > Q.10

Q1.1 Is your child currently waiting for a device?

Q.2 Which ones?

	1=	static seat
	2=	wheelchair
	3=	walking frame
	4=	walking stick
	5=	glasses
	6=	adapted cutlery
	7=	toileting aid
	8=	communication board
	9=	hearing aid
	10=	glasses
	11=	other

Q.3 How satisfied are you with the device? Very satisfied/ satisfied / neither satisfied nor dissatisfied / dissatisfied / very dissatisfied
(if received more than one device think of the MAIN assistive device you use)

Q.4 Who provided the device? Facilitator / Rehabilitation Clinic / NGO / Family / other Free text box
4.1 other : please specify

Q.5 When did you receive the device? Over 12 months ago / 12-6 months ago / 6- 3 months ago / 3-1 month ago / within last month

Q. 6 Does the device need any repairs? Yes / No If yes > open text box asking for details

Q.7 Were you given any information or help/training on how to use your child's device?
Complete or full information / Some information / No Information / Don't know or can't remember

Q.8 In addition to this device, do you think your child needs any other assistive devices?
Yes / No If yes > Q.8 If no > Q 12

Q.9 Which ones?
Then skip to Q.12

	1=	static seat
	2=	wheelchair
	3=	walking frame
	4=	walking stick
	5=	glasses
	6=	adapted cutlery
	7=	toileting aid
	8=	communication board
	9=	hearing aid
	10=	glasses
	11=	other

Q.10 Do you think that your child needs any assistive devices?

Q.11 Which ones? Circle

	1=	static seat
	2=	wheelchair
	3=	walking frame
	4=	walking stick
	5=	glasses
	6=	adapted cutlery
	7=	toileting aid
	8=	communication board
	9=	hearing aid
	10=	glasses
	11=	other

Q.12 Have you made any changes to your home to make things easier for your child?
Yes / No If yes > Q.13 If no ? Q.14

Q.13 What are the two main changes that you have made?
Open text box

Following questions to be answered by the interviewer based on observations and do not have to be asked verbally unless it is not possible to observe

Q.14 What main material is the device made from?
Paper or cardboard / plastic / metal / wood / mix / other

Q.15 Please complete the following observations of the accessibility of property:
- from road to threshold Level / steps
- door threshold into property Step / ramp / level
- internal floor surface Smooth / steps / rough or uneven Note - you might ask this at the start of the interview
- seating Standard / adapted / none (assessed by asking caregiver to sit the child)
where they normally are in the day after taking the anthropometric measurements

K. We now want to ask you about the goals which you set for your child at the start of the training last year
(Review the goals set set by parents & facilitators & select the top 2 priorities (top 2 physically on the list).

Priority	**What changes have there been** 1=No change 2= Some small improvement 3=Good Improvement 4=Excellent Improvement	**How satisfied are you with the changes** 1=Not satisfied 2=Fairly satisfied 3= Satisfied 4=Very Satisfied

Q1 : Priority 1 (Copy from home information sheet)

Q1 b. List any challenges which remain with acheiving this goal

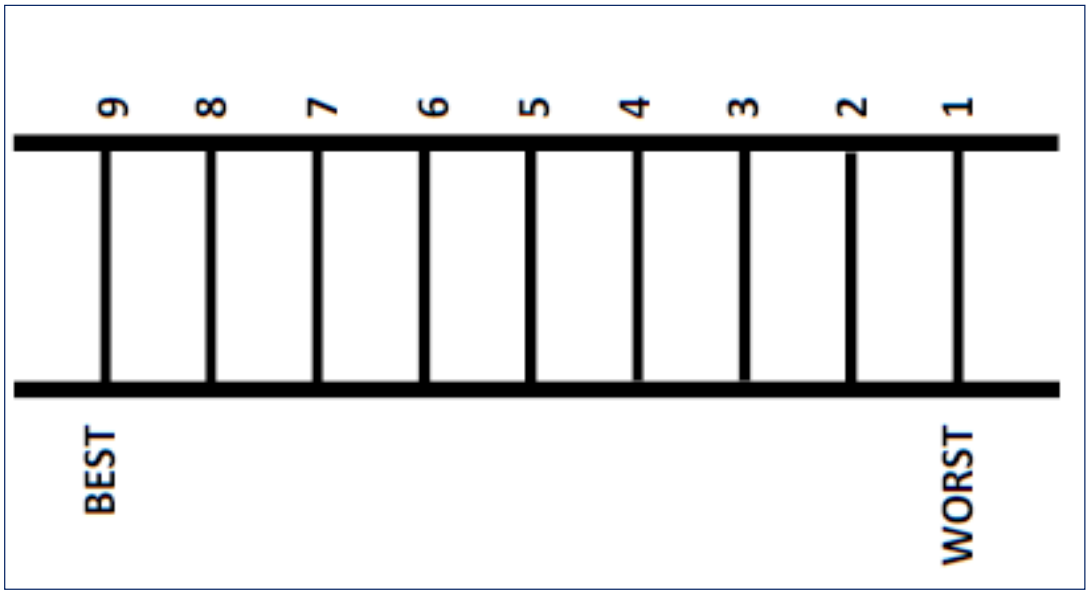
Q2: Priority 2 (copy from home information sheet)

Q2 B. Are there any challenges which remain with acheiving this goal

Q3 Are there any other important goals which your child has achieved? (specify)

Make judgement call in piloting phase - may want to drop the "other" Q 3

General observation about how quality of the goal setting and how SMART the goals are (Record on nexus or separately)



YOUNG LIVES LADDER

M. Training evaluation questions

We now want to ask a few questions about the training groups that you have a

1 The parent group meetings

Would you recommend this training to other families with CP

If no or not sure, main reason why

If Yes - Q2

2 What did you find most useful in the training?

	1=	Meeting other parents with a child with CP at group meetings
	2=	Learning about what causes your child's condition
	3=	Developing new skills for caring for your child e.g. feeding/commun
	4=	Learning about Disability Rights
	5=	Gaining confidence in how to look after your child
	6=	Learning from other parents
	7=	Learning from the facilitators
	8=	Having a home visit
	9=	Other (specifiy)

2.b Are you continuing to meet up with any caregivers in the group since completi

1=yes

2=no

Appendix 10: Qualitative Interview Guides: Baseline, Mid-term, Endline

Qualitative baseline-term interview guide: May 2015

This interview will be in several components:

Main interview to the primary caregiver

Second interview to the child if > 8 years (See separate sheet)

Third interview to another family member as identified by the primary caregiver.

Introduction:

Good morning and thank you for your time. I am _____ I am here today to as part of the research study we discussed before and which you kindly agreed to take part in. Your child has been assessed recently by ----------(CBM partner details) and you have been asked to join a parent training support group which will start in

……..

The purpose of today's interview is for us to better understand the lives of families of children with disabilities, and the support that you have in caring for your child. We will also want to talk to someone else in the family who helps you in caring for their child. We will ask you who that is

Remind them of the issue of confidentiality which is fully explained in the info sheet.

You can stop me at any time if something is unclear. If there us anything that you do not want to answer then you do not need to.

Interviewee:

Code: District/village name/order of interviews

Interviewer:

Date:

Site:

General Observations:

Where is the child at time of interview, interaction between parent and child, is the child playing, and who with.

Your family:Can you tell me about your family

Prompts: Who lives in the house, no of children, (no need for detail as this will be covered by the quantitative baseline) who goes out to work, who is the head of the household. If primary caregiver living on her own, explore why that is the case.

Your child with cerebral palsy

Can you tell me about your son/daughter (child X) and what you know about their condition? What do you think caused this condition? What have you been told about the condition? By whom?

Daily life of caregiver and child

I want to better understand how this condition affects your child by looking at what your child does during the day, and what you do during the day?

Highlight what kinds of activities she/he (child x) **is able** to do in the house? E.g. Dressing/feeding/washing him/herself, able to help with household chores, school work,

Could you tell me what she does outside of the house ? able to attend social events e.g. attend church, playing with other children?

Are there any things are more difficult or not possible for your child, that other children of the same age do? Or compared to their siblings. Explore why more difficult .What is it that makes some of these activities more difficult? (Physical access/about being welcome to events/other children do/don't come to play etc.)

Is child X going to school? If not explore why not, main reasons?

Describe the type of things that interfere with your child's participation in the above-mentioned

Please describe the type of things that help with your child's participation in the above-mentioned activities.

Networks of support

We would, like to understand who helps in caring for child X.

Who is doing the main caring (mother /father/siblings) for child X. Is there anyone else who helps-– in what way to they help you/your child. Explore the nature of that support. If father isn't mentioned ask why they are not involved in the caring role.

Other people who might provide support? Probe for people beyond the immediate family in the house? Neighbours? In-laws. Explore the nature of their support?

When was the last time you had a problem and you needed some support with. Who did you go to for some support?

Community groups that they belong to, other organisations who are helping them? The church? (v imp in Ghana)

Have they joined any support groups for parents with disabilities? Are they aware of any such groups? Do they know of any other children with cerebral palsy in their own community? If they have been linked into any such group how has it helped (In theory they have been chosen as they have not been a member of such a group)

Exploring attitudes towards disability & levels stigma

Refer back to the networks diagram and level of support they receive.

If they are getting *littl*e support explore why - Why do you think you are getting very little support? How do you think other people view your child's condition? Family attitudes/community attitudes?

If getting some support for your child. How do you think other people view your child's condition? Family attitudes- your in-laws/community attitudes?

Understanding access to health and rehabilitation services

We also want to understand what health and rehabilitation services you have used. Check they understand 'rehabilitation services' eg. Seeing a physiotherapist

Are they accessing any rehab services? Has this helped? Why? Why not?

Has their child received an assistive device – ask to see it if the child is not obviously using it. How has it helped

Have they heard of the Disability Fund? Have they accessed that? In what way has it helped?

Understanding the impact of caring

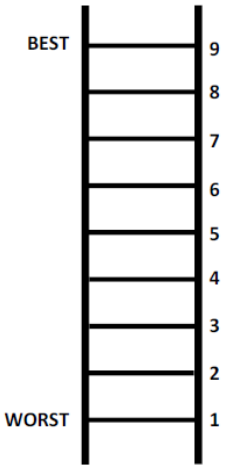
Refer back to the daily activities and caring cycle:

Which part of the day is more enjoyable for her (the caregiver)? Why? And which part of the day is more difficult, and why?

Use the Young Lives LADDER – (we plan to use this in the quantitative with pre-coded answers) but good to explore it in the qualitative with small no of families.

Now, display the card of the ladder with 9 steps (Figure #7).

Figure #7: Ladder Card



Explain that the ninth step, at the very top, represents the best possible life for the caregiver and the bottom represents the worst possible life for. Make sure that the caregiver understands that the ladder refers to all aspects of his/her life (economic, health, social, personal, etc.) and that it is a subjective measure of how he/she feels about his/her life in general. It should not be confused with a measure of economic wellbeing

95

There are 9 steps on the ladder. The top step represents the best possible life for you and the bottom represent s the worst. Where do you feel you are on the ladder at this present time?

What would help you move up the ladder – can be a number of things- explore why

What would cause you to move down the ladder- can be a number of things – explore why

Anything else that we haven't covered about caring for a child that you would like to add?

If time allows: Ask them to show you round the house to look at the environment where the child plays, the sanitation facilities – talk as you are going around the house about where the child spends most of her time, and other issues which may emerge to provide a more rounded view of the context.

Thank you for your time

Qualitative mid-term interview guide: Nov 2015

Preparation:

Check on baseline interview and baseline data in advance of each interview to develop specific probes for each family.

Interview the facilitator about the family

To take: Copies of photos from the first interviews to give to families

Check if child has received an assistive device

Introductions and outlining purpose of today's interview and

Observation of any changes in the context since the last visit:

Where the child is sitting, engaged with an activity -Child able to sit/using an assistive device/playing with toys/child looking happy & engaged with an activity

General health and well-being of the child

How has X been since our last visit in May?

What changes has she seen? What has brought about those changes? (links to nutritionist, changes in care practice, access to HIC card, access to an assistive device, home visits, learning in the group etc)

What has been the most important change that she has seen? Why important….(e.g. able to lie child down and free up time for working)

Do you think life for your child is getting better? If so in what way?

Do you think you have changed in how you are caring for your child? How? (Prompts - How you position him/her? Do you think you are more patient? Why?)

Changes in feeding – what child is fed, how you feed him? Anything which is still difficult? Any links in the community – with nutritionist etc. (a particular issue given v high levels of malnutrition)

Any changes in the home environment- interactions with the family -

Experience of the parent support groups & home visits (check if they have been regularly attending)

Please tell me about the group that you are going to? Anything you like about the groups? Do you like attending? Any sessions you have particularly liked? Why? Any difficulties with attending? Would it just be easier if you had home visits? Explore why?

(Note: parents often talk in very general terms about the sessions, so to be more concrete ask about the last session- what if anything they found useful/liked/disliked)

What have you been learning in the groups – ask to see the handouts – good to ask if they have shared these materials with anyone else in the family

Relationship with the other caregivers. Please tell me about the other mothers in the group. Did you know any of them before? Do any of them live locally? Explore if any contact with groups members outside of the meetings? If so, do they meet up between meetings

What they value from the group?

If not attending regularly – understanding main reasons for this Tell me about the home visits from X

Explore ‘added’ benefit of going to the groups vs just home visits

General health and well-being of the caregiver

We have been talking a lot about X, now I want to ask you how you are?

Is life getting any better for you? Or worse?

(prompt – now able to work, do household chores, less exhausted? emotionally – understand more, more worried/less worried? Communication – with other families members, get more help from other family members)

To get a more concrete example – ask about something that has happened to the child recently – such as taking to a family event – how did they feel about that

Wider learning in the family /community

(How is the learning in the parent groups being translated into changes at home and engagement with other family members)

Do you feel there is greater understanding in the family of your child’s condition? Why? Why not? How do they know this – perhaps a concrete example

Can you share with me the parent handout – has it been useful to have this? Shared with other family members (despite being in English?) have you been able to share any learning from the group?

Greater understanding in the community? In what way? (huge levels of stigma, beliefs that child a spirit child- what can you say to people? Have you shared any of this information with other neighbours etc.)

Support networks

Where do you go to for support if you have a problem about your child – who do you talk to? (ask the facilitator, bring problem to group)

Overall, do you think your life is getting better for you? And your child? What would improve the quality of your life more?

Other: Thank you for your time and for sharing your experience of the training with us. Other parents in Ghana will benefit from your stories. Is there anything else important which I haven't asked you which you want to share with us?

Endline Qualitative Interview guide: Getting to know CP

Final

Materials & preparation:

Preparation: print our interviews and summarise key issues to further explore for each individual family based on the last visit.

Print out pictures from the last visit

Ask for pictures of each group – print out and use for prompting

Copy of the 'ladder'

A total of 14 interviews

Overall aim: To explore if here have been any changes over the last 6 months

How these changes came about (underlying processes and 'empowerment' within that journey).

To follow up on some very specific issues since the last visit for each family

To follow up with secondary caregivers about their perception of any changes

Introductions and outlining purpose of today's interview

Observation of any changes in the context since the last visit:

Where the child is sitting, engaged with an activity -child able to sit/using an assistive device/playing with toys/child looking happy & engaged with an activity

General health and well-being of the child

How is (insert child's name) since I last visited?

Has anything changed? Explore in concrete terms e.g. Functional changes, what brought that about , change in general health of the child, child feeling happier, child able to go to school

For each change – explore further what the caregiver thinks has brought about that change

Individual factors e.g, change in knowledge/understanding, a change in practice- what was it?

Assistive devices e.g, new chair, different equipment for feeding etc- can I see – how has this helped

Family level changes: more support in the family, change in attitudes of family- more help in the house?

Wider changes: Referrals and links to other services e.g. access to nutritional support/schools. What did that support look like – can you take me through the last time e.g. last visit from the community nutritionist.

Other?

Livelihoods – last time I saw you explained that you were not able to pay for X …….you were not able to work- has this changed? In what way?

How do you feel about these changes?

Insert specific follow up probes for each family which will vary:

Use of the assistive device- can I see the assistive device-what has it allowed the child to do?

Support around nutrition- what did that mean – can they take me through the last visit to the nutritionist, changes in food, feeding practice

Child's general health (physical and emotional)**. How has your child's health been over the last 6 months (from last Christmas)?** If hasn't been well explore what caregivers did? Use of local health services – payment for services? An up to date health insurance card?

Most Significant Change. Looking over the changes, which do you think is the Most Significant Change for your child? Why? **For You what has been the most important change**

The role of the support group

Have a copy of the training manual and pictures of the group and group activities as visual prompts.

Can you tell me what is happening in the pictures- who are the other families in the group, what are you doing in this activity? (show 2-3 pictures).

So can you tell me how your support group works? Is it still meeting?

How did you find the group? Good things? Any sessions you have particularly liked? Didn't like?

Can you tell if there is anything that you value about the group? Probe around not just learning new things and general comments but on the value of being a member with other caregivers

Prompts: Meeting other mums, Being able to share your problems?

Do you find other mums share their experiences? In what way? Is it just focussing on their child?

Learning from others ?

Language?

Would it just be better if you had home visits? Explore why/why not?

Joint group activities: Has your group organised anything together/planning to organise something e.g, a Durbar? Community meeting? How has that come about? How do you feel about that?

If you were to say ONE thing that was of most importance to you from the support group, what would it be?

If the family was not able to attend regularly? And if not, why not (will have the attendance data so probe on families who missed sessions

Now that the group has stopped are you in touch with anyone? Plans to stay in touch? If not, why not?

The role of the home visit

Refer to the parent handouts.

Reflect back on last visit and whether this material was being shared with other family members- have you been sharing it? Have you had time? Family members interested?

What are your views on the home visits – how have they worked? Do they help? In what way? Are other family members involved at all, and if so, in what way? Has that made any difference in terms of caring for child X?

Changes for you as the caregiver

We have been talking a lot about X, now I want to ask you how you are?

Has life changed for you over the last year? If so, in what way?

Prompts around changes Individual: changes in how you understand things, Family: changes in support, wide support group or community support)

Prompts – now able to work more/less, do household chores, less exhausted? emotionally – understand more, more worried/less worried? Communication – with other families members, get more help from other family members)

To get a more concrete example – ask about something that has happened to the child recently – such as taking to a family event – how did they feel about that? When the child started to feed better/attend school?

Re-visit the Ladder. A year ago I has his ladder and I ask you to tell me where you thought you were on the ladder – can you remember that (explain the ladder exercise again).

Where do you think you are on the ladder at the moment? Why? Is that an improvement from last year or not? What do you think has helped improve things? What has stopped any improvement? Why do you think life has changed/not changed?

And where would you now put your child on the ladder in terms of the quality of their lives? What would improve it further, and why? What could make it worse, and why?

Support network? Who do you go to support? So if you have a problem now with child X (for example refer back to an example from the ladder), who would you go and discuss this with?

In your role as caregiver, What is the **Most Significant Change** for you over the last year?

Wider learning in the family /community

(Exploring here how is the learning in the parent groups being translated into changes at home and engagement with other family members)

Do you feel there is any change in how other family members view your child's condition? Why? Why not? What does that mean in practice? Who looks after the child when you need to work? How do they know this – perhaps a concrete example

Refer to the parent handout – has it been useful to have this? Shared with other family members (despite being in English?) have you been able to share any learning from the group?

Greater understanding in the community? In what way? (huge levels of stigma, beliefs that child a spirit child- what can you say to people? Have you shared any of this information with other neighbours etc.) How did this come about? Do you think it's really making any difference? (group activities, role of the facilitator)

Other

Thank you for your time and for sharing your experience of the training with us. As we think about conducting this training and home visits with other parents, is there anything else important which I haven't asked you which you want to share with us? Other recommendations?

Appendices Part 2 Supplementary papers

This second set of appendices consists of four papers:

- Zuurmond, M., Mahmud, I. & Hartley, S. 2018. Children with cerebral palsy in Bangladesh: Their contribution to the development of a rehabilitation training programme. *Disability, CBR and Inclusive Development,* 29**,** 25-42.2.2 Zuurmond, M., Mahmud, I., Polack, S. & Evans, J. 2015.
- Understanding the Lives of Caregivers of Children with Cerebral Palsy in rural Bangladesh: Use of Mixed Methods. *Disability, CBR & Inclusive Development,* 26**,** 5-21.
- Polack, S., Adams, M., O'Banion, D., Baltussen, M., Asante, S., Kerac, M., Gladstone, M. & Zuurmond, M. 2018. Children with cerebral palsy in Ghana: malnutrition, feeding challenges, and caregiver quality of life. *Developmental Medicine & Child Neurology,* 60**,** 914-921.
- Donkor, C. M., Lee, J., Lelijveld, N., Adams, M., Baltussen, M. M., Nyante, G. G., Kerac, M., Polack, S. & Zuurmond, M. 2019. Improving nutritional status of children with Cerebral palsy: a qualitative study of caregiver experiences and community-based training in Ghana. *Food science & nutrition,* 7**,** 35-43.

Children with Cerebral Palsy in Bangladesh: Their Contribution to the Development of a Rehabilitation Training Programme

Maria Zuurmond[1], Ilias Mahmud[1,2]*, Sally Hartley[3,4]

1. London School of Hygiene and Tropical Medicine, London, UK
2. College of Public Health and Health Informatics, Qassim, Saudi Arabia
3. The University of East Anglia, Norwich, UK
4. The University of Sydney, Australia

ABSTRACT

Purpose: *Although cerebral palsy is the most prevalent health condition linked to childhood disability in Bangladesh, support and rehabilitation for this group is limited and intervention development is slow. An initiative to address these unmet needs was the development of a parent/caregiver training programme for the rehabilitation of children with cerebral palsy. The aim of this study was to explore what was important in the everyday lives of children with cerebral palsy in rural Bangladesh and take their views into account to inform the training programme.*

Methods: *Qualitative data was collected from 12 children with cerebral palsy, between 5 - 14 years of age. The children were purposively selected from among those who attended the training programme. A participatory method called the 'Feeling Dice' was used to elicit children's feelings about their everyday lives. The approach was easy to use, acceptable in the local context, the children enjoyed the activity, and it generated rich information.*

Results: *'Inclusion in play' and 'being able to attend school' made the children happy and were their two main priorities, yet were not key issues for parents. The children were frustrated by their dependence on others for day-to-day activities such as feeding, bathing, and transport to school. Children also played an important part in encouraging their parents to attend the training course.*

Conclusion: *This study showed that valuable information can be gathered from children with cerebral palsy by using a simple and adaptable participatory research tool. Children's views and priorities sometimes differed from those of their parents and carers, and is useful for developing more relevant and*

* **Corresponding Author:** Ilias Mahmud, Assistant Professor, Qassim University, College of Public Health and Health Informatics, 8848 King Abdulaziz Rd, Bukayriah, Qassim, Saudi Arabia. Email: imahmudot@gmail.com

valid interventions. Children need to be recognised as important 'agents of change' within their own rehabilitation. This methodology is in harmony with the UNCRPD recommendations, and supports inclusive and rights-based intervention development.

Key words: *Rehabilitation, cerebral palsy, children's rights, disability, health, inclusion*

INTRODUCTION

Cerebral palsy is one of the most prevalent health conditions for children with disabilities in low- and middle-income countries (UNICEF, 2013). It is a motor disorder, but often children with cerebral palsy will have associated impairments such as hearing, visual, and cognitive impairments (Colver, 2014). Despite their wide-ranging needs, support and rehabilitation services for these children and their parents are scarce or non-existent in low- and middle-income countries (World Health Organisation and World Bank, 2011; UNICEF, 2013).It is well documented that these children are often socially excluded, and frequently lack access to primary and rehabilitative healthcare, and education (WHO and World Bank, 2011; UNICEF, 2013). The Convention on the Rights of the Child, and the Convention on the Rights of Persons with Disabilities direct governments to be responsible for ensuring that all children, irrespective of any disability, enjoy their rights without discrimination (United Nations, 1989; 2006).

A recent survey of childhood disability in Bangladesh, using a key informant methodology, estimated the prevalence of moderate or severe disability at 7.2 per thousand children (Mactaggart and Murthy, 2013). Cerebral palsy made up the greatest number with a prevalence of 3.7 per thousand children and accounted for more than half of the children with a moderate or severe physical impairment. Extrapolating these estimates to the whole country suggests that there are nearly a quarter of a million children with cerebral palsy in Bangladesh. However, this estimate is much lower than the global estimate (1 in 20) of children with moderate or severe disability of some kind (UNICEF, 2013).

Article 7 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) addresses the obligation States have to hear the views of children with disabilities in all matters which concern them. However, it is commonly argued that children and young people are often the least consulted

and most voiceless group at all levels within the family, community and wider political arena (Harper and Jones, 2008). Children with disabilities are often doubly disadvantaged, firstly because they are children, and then an additional layer of marginalisation because they are disabled (Beresford, 1997). Powell and Smith (2009) reported that those who have conducted research with children suggest that children's participation rights are particularly compromised when they are considered vulnerable and the research topic is considered to be sensitive. They argued that children should not be viewed as vulnerable passive victims but as social actors who are able to take decisions about participation in research; hence, they should have a more central role in decision-making about participation when research is about them. Although there is an increasing focus on promoting the active participation of children in research (Boyden and Ennew, 1997; Alderson, 2008) there is still limited children-centred participatory research among children with disabilities in LMIC settings.

Although Bangladesh was one of the first countries to sign and ratify the United Nations Convention on the Rights of the Child (UNCRC), a literature review for the current study was unable to identify any childhood disability rehabilitation programme in Bangladesh which had consulted children with disability in order to understand their priorities and opinions. With the ratification of the UNCRC there is now a clear legal framework for encouraging children and young people to participate in making decisions that affect their lives.

Despite cerebral palsy being a common form of childhood disability in Bangladesh, support and rehabilitative services available for these children and their families are very limited. To address this unmet need, a parent training programme was developed on rehabilitation and management of children with cerebral palsy in resource-poor settings, recognising the fact that parents and carers are at the frontline of caring for their children with cerebral palsy (London School of Hygiene and Tropical Medicine and Hambisela, 2013). The parent training programme sought to empower parents and caregivers to improve the quality of care for their children with cerebral palsy. The programme was developed and its relevance and acceptability were evaluated through action research with the families and children. Parents/caregivers participated in the training course along with their children with cerebral palsy.

The objective of this study was to explore what was important in the everyday lives of children with cerebral palsy in rural Bangladesh to inform the parent/

caregiver training programme on rehabilitation and management of these children. This paper reports on one component of this action research with children who participated in the training programme.

METHOD

Sample

A purposeful sample of children was selected from a larger group of 153 children with cerebral palsy in two sub-districts of Sirajganj district of Bangladesh. This larger group of children had been identified in a previous survey of childhood disability (Mactaggart and Murthy, 2013) and had participated in a parent training programme for improving the care and support of children with cerebral palsy in resource-poor settings. All the children had been clinically diagnosed two years previously by a paediatrician and were identified as having a moderate or severe level of cerebral palsy.

Inclusion criteria for study participants:

- Children from 5-14 years of age,
- A balance of both genders,
- Varying levels of severity of cerebral palsy as identified by community workers,
- A geographic spread across two sub-districts.

All the families were registered to participate in a research project to develop a training programme for parents and caregivers of children with cerebral palsy. Twelve children were interviewed: 7 females and 5 males. All the children, with one exception, were intermittent school-goers, often attending only 2-3 days per week. Further details of the children are presented in Table 1.

Study Design

A participatory approach was used for interviewing the children. Many issues were taken into consideration in the choice of a participatory tool for 'interviews' with the children. Participatory methods have a range of benefits: they are generally more visual, do not require high levels of literacy, they can be useful for sharing information, and promote learning and empowerment (Chambers, 1994).

Table 1: Characteristics of the Study Participants

Pseudo-nyms	Age	Gender	Family economic status*	School attendance	Functionality description- mobility, communication and self-care
Sumona	14	F	Poor	Grade 1 Irregular	Could not sit, stand or walk without support. Severe difficulties in speaking. Needed maximum assistance for all aspects of self-care.
Asma	12	F	Poor	Grade 1 Irregular	Some mobility difficulties. Left hand was very weak. Needed moderate assistance with toileting and other self-care activities.
Ayesha	8	F	Middle class	Grade 1 Regular school attendance	Could walk with some difficulties.
Jahid Hasan	12	M	Middle class	Grade 5	Difficulties in speaking, could not do anything with right hand, weak right leg, assistance required with self-care.
Tuba	5	F	Rich	Not school-going age	Could not walk or stand unaided. Assistance required with all aspects of self-care and play activities.
Shathi	11	M	Poor	Grade 1 Intermittent school attendance	Difficulties with mobility, limited use of hands, poor eyesight, difficulties with speaking. Needed assistance with self-care such as dressing and toileting.

Likhon	9	M	Poor Lives with adopted parents	Grade 1 Intermittent school attendance	Weak right leg and hand, difficulty with comprehension and speech. Required support with some aspects of self-care, e.g. dressing.
Raihan	7	M	Lower middle class	Grade 1 Regular school attendance	Some difficulties in using right hand and legs. Could perform self-care with some difficulties.
Samiul	11	M	Lower middle class	Grade 3 Regular school attendance	Could walk with some difficulties; little difficulties in speaking; poor eyesight. Some difficulties in self-care.
Lata	6	F	Poor	Grade 1 Regular	Could walk with some difficulties. Could perform self-care independently with some difficulties.
Halima	7	F	Poor	Grade 1 Intermittent school attendance	Could not stand or sit for a long period because of weakness in legs and hands. Frequently suffers from cold and fever. Support needed in self-care.
Bonna	11	F	Poor	Grade 1 Intermittent school attendance	Limited mobility- can walk with mobility aids. Needed minimum assistance in self-care.

* assessment made by the community health workers

It was important that the study activity should encourage active engagement of the children and should be appropriate to use in the rural context of Bangladesh. A central tenet of the parent and caregiver training programme was about encouraging children's development through play activities, therefore the research activity aimed to complement this. As the target group was children with a range of severity of cerebral palsy, another consideration was that the activity

chosen should be tactile, and that children with limited motor skills could engage with. It also had to be a tool which did not require children to be literate, taking into account the low level of schooling. A significant proportion of children with cerebral palsy may have cognitive, visual, and hearing impairments, and therefore the tool needed to be adaptable to differing needs.

The tool that was chosen was the 'Feeling Dice'. This tool was originally used in a study to explore children's feelings, in order to understand experiences of marginalisation in primary school (McNamara and Moreton, 1995). Accordingly, a giant colourful dice was used because it would be more tangible to touch, easy and lightweight to hold, and had large simple pictures of emotional expressions that were easy to understand. On each face of the dice was a picture with a different feeling, and according to whichever side of the dice was shown when it was thrown, the children were prompted to complete a sentence, "I am happy when…, I am sad when…., I am frustrated when…, I am angry when.....". Prompt questions were then used to explore the issues further. Additionally, specific prompt questions about the training programme were included, to find what they liked/disliked about the training on offer. The children were encouraged to keep throwing the dice until the data was saturated and no further issues arose.

After some piloting it was decided to use a large colourful dice (12cm x 12 cm) with mini white boards on each face. The added advantage was that children could easily draw their own pictures depicting each emotion onto the dice, and therefore did not need to interpret someone else's drawings. In practice any type of giant dice, locally made, would suffice.

Figure 1: The 'Feeling Dice'

Data Collection

The activity was initially piloted during a group training session, but the chaotic environment of the meetings precluded the possibility of finding a quiet space to engage with the children. It was therefore decided to conduct activity in the home setting during follow-up home visits. This enabled the interviewer to build rapport with the child and family, and the quieter environment was important for children who needed additional support with communication.

In all cases the children were 'interviewed' on their own, except where they expressed a preference to have someone with them, and/or a caregiver was needed to help with communication. This was sometimes challenging because typically, in rural Bangladesh, households often consist of only one room with many family members living together. This mirrors similar methodological issues raised in qualitative research conducted in India (Singal, 2010). It was made more feasible in this research because the interviewer had built up a relationship of trust with the families during the training course, and therefore was known to family members, as well as the child. Familiarity with the researcher and the fun nature of the activity was important to minimise any feeling of distress felt by the child.

Some children required help with drawing the pictures, and some children needed to have the pictures drawn for them, while at the same time checking that they were happy with the illustrations and the feelings depicted. For children with more limited communication, additional pictures were used, and they were asked to point to illustrations of what they enjoyed doing, with closed questions asked, which required only a 'yes' or 'no' answer.

The researcher was also sensitive to any verbal and body language cues which indicated that the child wanted to discontinue the activity. In three cases the activity was not completed in one visit because the children were tired; they were then completed during a follow-up home visit.

Data Analysis

Detailed notes of all the interviews were written down by the interviewer in the local language and then translated into English. Notes were made on the experience of using the dice as well. Data was managed using NVivo10 data management software and a thematic content analysis of the children's interviews was undertaken. The analysis was underpinned by an interpretive phenomenological approach to the collection and interpretation of qualitative data (Green and Thorogood, 2009; Creswell, 2014).

Ethical Considerations

Ethical approval was obtained from the ethics committees of LSHTM and The Child Sight Foundation. The project took into account particular ethical issues of gathering information from children in international settings (Schenk and

Williamson, 2009), as well the guidance for research among children with disabilities (Alderson and Morrow, 2004; Beresford, 2012). Written consent was sought from the parents and verbal consent from the children.

RESULTS

This section reports on the research process of testing the 'Feeling Dice', as well as the reported experiences of the children.

Process

It was found that all the children, of different ages and abilities, responded positively to the activity and wanted to engage with the 'research' for longer periods of time, even up to an hour or more. The activity prompted discussion even among children who were generally very quiet. Most of the children in this setting were not used to having toys, but it was still an activity which was easy for them to understand and engage with, and they clearly enjoyed the opportunity of throwing the dice. After the 'interview' was completed, playing with the dice was sometimes turned into another game. Making the process more participatory and fun resulted in children being happy to stay engaged.

Over the course of the project the researcher had become a familiar figure to the children through the parent training sessions, and in many 'interviews' they referred to him affectionately as 'uncle'. The researcher felt this sustained contact and resultant level of trust as an important factor in building the children's confidence so that they could discuss their feelings openly.

Main Findings

What makes children happy?

In the rural Bangladesh context, there were four main sub-themes regarding what makes children happy: play, school attendance, being loved by their family, and enjoyment of their favourite everyday activities, such as eating their favourite food.

Consistent across every interview, the most important thing which made children happy was being able to play with other children. Play was also the main reason why children liked going to school and to the training sessions, as it afforded them the opportunity to meet with friends.

> "When I go to school, I can play with my friends – that's why I feel good" (Lata, 6-year-old female).
>
> "I feel happy when I play. [What kind of games do you like?] I like to play with toy cars. I like to play with other children at home and at the school..... I like to go to school very much. [Why do you like to go to school?] I like to go to school because I can play with everyone at the school" (Samiul, 11-year-old male).

The second most common cause for happiness, identified by all children of school-going age, was attendance at school. As discussed, the main reason was because of opportunities at school to meet and play with friends. The second reason was because the teachers were helpful, respectful and caring. The least common reason given for attending school was because of the lessons.

> "I like to go to the school. I never miss school even on rainy or stormy days. [Why do you like to go to the school?] I like it when my friends come and chat with me. The teachers are very nice and give lessons and never scold me. They love me and take care of me. They always call me by name and ask about my well-being...that's why I like them" (Jahid, 12-year-old male).

All the children identified being loved and cared for by relatives as something which made them very happy. Children had individual favourite everyday activities which they enjoyed; these included events such as eating their favourite food or being bought sweets.

What makes children sad?

The terms 'unhappy', sad', 'angry' and 'frustrated' were used interchangeably in the children's discourse and brought up similar issues; hence they are addressed together here.

The two main themes for the cause of unhappiness were: not being included in play and not being able to attend school. There was also mention of stigma and bullying, and frustration with being dependent upon others for some daily activities. Although children wanted to attend school, it was also a context in which they felt excluded and were sometimes bullied by other children.

Not being included in play was the most commonly reported issue for unhappiness, identified by two-thirds of the children.

> "When all the children play around in the school and back at home, I feel sad because I can't run. I also wish to be able to run and play" (Asma, 12-year-old female).

Another commonly cited reason for children being unhappy was their inability to attend school. The main barriers were transport to and from school, and dependence on a parent or some other person to carry them or accompany them to school. Parents usually lacked time to convey their children, or were sometimes not well enough to escort them. For example, one child could walk with the aid of a stick but needed someone present to provide extra support in case she fell.

> "My mother now can't take me to the school regularly anymore. When she is sick [pregnant] she can't take me..... If I was healthy [no disability], then my mother would not have to take me to school. When I see the pain of my mother, I feel like leaving school. ..... I walk on a stick and I rest every now and then. It's very painful for me. Sometimes I cry when it's too much painful for me. Sometimes when I really want to go to the school, but my mother can't take me – I cry. .....One month ago, my mother gave birth to a baby, and since then my mother can't take me to school" (Asma, 12-year-old female).

Being dependent on others for daily activities such as feeding, toileting and bathing were reasons for sadness, anger or frustration. In five of the participatory interviews, children described their frustration over waiting to be fed and difficulties with feeding. Having to find time to feed children was similarly highlighted by parents. For example, one 9-year-old boy described how he loved swimming and playing in the river with friends and going to school. However, he had a weak right arm and leg, and what made him angry was that he had to wait for his mother to feed him. He could feed himself with his left hand, but Bangladesh culture dictates that it is polite to eat only with the right hand.

> "[When do you feel sad?] I can't eat with my right hand. If mother doesn't want to feed me, I cry. I cry when my mother delays in giving me food when I am hungry" (Likhon, 9-year-old male).

A pre-teen girl mentioned a similar issue related to feeding.

> "When I am too hungry, my mum is away or busy, I cry. If I was healthy [no disability] today, I could have eaten rice on my own" (Asma, 12-year-old female).

Finally, in just under half of the interviews, being bullied or stigmatised by other children, family or community members, was identified as another cause of sadness. The community often views children with disabilities as worthless burdens on their family. They see no point in taking care of children with disabilities.

> "Sometimes people make fun of me. This makes me very angry. They say 'this child is not able to do anything; he only sits or lies down the whole day, so don't give him food'. These make me very angry" (Shathi, 11-year-old male).

Feedback on the training course

All the children said that attending the training made them happy, as did the follow-up visits conducted by the community workers. The main reason was because of the opportunity to play, and the second most common reason was the caring and loving attitudes of the trainers. Refreshments and learning new things were other reasons for their enjoyment. They commonly used an affectionate term, 'uncle', to describe the community workers.

> "The uncles [community workers] at the meeting care for me very much. They play with me too. I like that very much. The uncles and sir [trainer] teach us exercises, and after the meeting they give us biscuits and juice..... I can play with Anita [name changed] and others at the meeting. I didn't know them before coming to the meeting, and now we are all friends. I love to be and play with them" (Ayesha, 8-year-old female).

Similarly, half of the children said that being unable to attend the training course made them sad. Interestingly, although the training course was targeted mainly at the parents, it was clear from the children's 'interviews' that the children's eagerness to attend was very often a key driving factor for a parent or caregiver's attendance at the course.

> "I feel angry when they [my grandparents] do not want to take me to the meeting. When they do that I start to walk there by myself and they follow me" (Jahid, 12-year-old male).

> "Sometimes my parents don't want to take me to training because they are busy. Then I feel sad. When they find that I am really sad, they take me to the training" (Asma, 12-year-old female).

> "Sometimes my mother doesn't want to take me to the meeting because of too much work.... I cry in anger then. My father or my brother takes me to the meeting if I cry" (Ayesha, 8-year-old female).

Other factors which made them sad, reported by two children, included that they did not enjoy being forced to do exercises after the training.

DISCUSSION

Cerebral palsy is one of the most prevalent health conditions among children with disabilities in low- and middle-income countries (LMICs). It is a neurological health condition, but often children will have associated impairments such as hearing, visual, and cognitive impairments. However, despite wide-ranging needs, the rehabilitation on offer for these children is scarce or non-existent. From a rights-based perspective it is essential that when planning services which affect children, including children with disabilities, their views should be consulted (United Nations, 1989; 2006). This research adapted and trialled a participatory research tool, the 'Feeling Dice', to elicit the views of children with cerebral palsy in rural Bangladesh, and ensured that their views also contributed to the planning of a participatory training course for caregivers.

The study showed that using this child-centred participatory research encouraged a focus on play, was fun, and was an acceptable activity in which children could easily engage in the rural Bangladesh context. The large and tactile dice with simple pictures is easily adaptable for children with disabilities who may require extra help with communication, who may have sensory impairments, or have additional physical needs.

Importantly, as a result of listening to children, there was recognition of the need to prioritise schooling issues as part of any parent and caregiver training programme, identify avenues for improving attendance, and find strategies to improve inclusion in play, both in and out of school. Other studies on the rehabilitation of children with cerebral palsy in Bangladesh and other LMICs have sometimes focussed more narrowly on approaches for improving the health and physical functioning of the child as assessed by parents or therapists, the impact of caring on the caregiver, and barriers around the uptake or services (McConkey et al, 2000; Mobarak et al, 2000; Hartley, 2005; Maloni et al, 2010; Nesbitt et al, 2012; Bedford et al, 2013). This study highlighted the importance of a broader understanding of health and well-being, and the importance of being

able to engage in social activities, from the perspective of the child.

This study highlighted that some children described feeling frustrated and hungry while waiting to be fed. This complements findings from other studies on the particular challenges around feeding for children with cerebral palsy: children can have difficulty chewing and swallowing, the food served may require special preparation, in some cultural contexts parents can find it difficult to allow children to feed themselves because of the mess that is involved, and caregivers can lack the additional time which is required for feeding the child (Gangil et al, 2001; Yousafzai et al, 2003a; Yousafzai et al, 2003b; Adams et al, 2012). The current study provided a unique children's perspective on the issue, highlighting that it is not only the caregiver who gets frustrated in the feeding process. Furthermore, any intervention to address feeding must address the cultural barriers to independent feeding and consider the family dynamics around feeding, in order to find strategies to better support feeding.

This study also showed that children were often key drivers in determining whether parents or caregivers attended training. Their enjoyment was a major factor which influenced attendance; therefore, it is essential to ensure that training remains attractive and relevant to children as well as to parents. When children do not want to do exercises or use assistive devices, then it is, unsurprisingly, harder for parents to impose these. Yet, this engagement with children is often overlooked in intervention studies targeted at parents. The results indicate that, when planning training programmes, it is important to recognise that children are also important 'agents of change' in their own rehabilitation, and should be actively engaged as part of any programme.

Limitations

There were a few limitations to this study. Having a local Bangladeshi research assistant who became well-known to the families over the course of the year has benefits, as well as possible limitations. The presence of a familiar person at the interview can sometimes have both advantages and disadvantages. Disadvantages include possible inhibition of the child's responses and/or that the adults can act as a filter and put their own interpretation on the data (Morris, 1998). It is possible that the children felt they had to say that they enjoyed the training course because the researcher was identified as part of the training programme. However, the level of trust between the researcher and the family went some way to mitigate this. In one case the interviewer observed that the child felt unhappy

talking freely in his own home, and hence continued the interview during a walk outside the house.

One of the main limitations of the study was that ten of the twelve children (83%) were attending school, albeit intermittently, which was not typical of children with disabilities in this rural area of Bangladesh. An earlier survey in the same study area showed that only 39% of children with targeted impairments attended school, compared to 84% of children without impairments (Mactaggart and Murthy, 2013).

Another limitation was that although the study aimed to include children with a range of severity of cerebral palsy, the researchers were reliant on the community workers to choose a range of children, and there may have been a bias whereby those known to be more able to communicate were more typically sampled. Children with severe cognitive impairment were not included, and in any future project more time would be needed to adapt the approach further for this group of children.

CONCLUSION

This study demonstrates the importance of research which is inclusive of children with disabilities and gives an example of a very simple participatory tool which can be easily adapted to a variety of cultural settings. This methodology is in harmony with the UNCRPD and supports inclusive and rights-based intervention development.

Implications

Clearly, engaging with children with cerebral palsy is a practical option, even in resource-poor settings. The data yielded is informative for developing and enhancing interventions. Children and caregivers can provide different perspectives on their lives, and these are needed to ensure that interventions are valid, relevant and acceptable to both children and their families.

ACKNOWLEDGEMENT

The Child Sight Foundation (CSF) implemented this project in Bangladesh, led by the project manager M Monzurul Alam and supported by M Shafiqur Rahman. Khaled Hossain Joarder interviewed all children.

CBM International funded the research and development of the parent training

manual for children with cerebral palsy, available at http://disabilitycentre.lshtm.ac.uk/key-publications/getting-to-know-cerebral-palsy/

REFERENCES

Adams MS, Khan NZ, Begum SA, Wirz SL, Hesketh T, Pring TR (2012). Feeding difficulties in children with cerebral palsy: Low-cost caregiver training in Dhaka, Bangladesh. Child: Care Health and Development; 38(6): 878-888. https://doi.org/10.1111/j.1365-2214.2011.01327.x PMid:22082112

Alderson P (2008). Children as researchers: participation rights and research methods. In Christensen P, James A (Eds). Research with children: Perspectives and practices. New York, USA: Routledge: 276-290.

Alderson P, Morrow V (2004). Ethics, social research and consulting with children and young people. London: Barnardo's.

Bedford J, Mackey S, Parvin A, Muhit M, Murthy GV (2013). Reasons for non-uptake of referral: Children with disabilities identified through the Key Informant Method in Bangladesh. Disability & Rehabilitation; 35(25): 2164-2170. https://doi.org/10.3109/09638288.2013.770927 PMid:23480675

Beresford B (1997). Personal accounts: Involving disabled children in research. London: The Stationery Office.

Boyden J, Ennew J (1997). Children in focus - A manual for participatory research with children. Stockholm: Save the Children Sweden.

Chambers R (1994). Participatory rural appraisal (PRA): Challenges, potentials and paradigm. World Development; 22(10): 1437-1454. https://doi.org/10.1016/0305-750X(94)90030-2

Colver A, Fairhurst C, Pharoah POD(2014). Cerebral palsy. The Lancet; 383(9924): 1240-1249. https://doi.org/10.1016/S0140-6736(13)61835-8

Creswell JW (2014). Research design: Qualitative, quantitative, and mixed methods approaches.Thousand Oaks, California: SAGE Publications, Inc.

Gangil A, Patwari AK, Aneja S, Ahuja B, Anand VK (2001). Feeding problems in children with cerebral palsy. Indian pediatrics; 38(8): 839-846. PMid:11520994

Green J, Thorogood N (2009). Qualitative methods for health research. London: SAGE Publications Ltd.

Harper C, Jones N (2008). Why are children's rights invisible? [Online]. Available from: https://www.odi.org/sites/odi.org.uk/files/odi-assets/publications-opinion-files/3371.pdf [Accessed on 11 March 2019].

Hartley S, Ojwang P, Baguwemu A, Ddamulira M, Chavuta A (2005). How do carers of disabled children cope? The Ugandan perspective. Child: Care, Health and Development; 31(2): 167-180. https://doi.org/10.1111/j.1365-2214.2004.00464.x PMid:15715696

London School of Hygiene and Tropical Medicine, Hambisela (2013). Getting to know cerebral palsy: Working with parent groups - A training resource for facilitators, parents, caregivers, and persons with cerebral palsy [Online]. Available from: http://disabilitycentre.lshtm.ac.uk/files/2013/06/Getting-to-know-cerebral-palsy-v1-hires.pdf [Accessed on 11 March 2019].

Mactaggart I, Murthy GVS (2013). The key informant child disability project in Bangladesh and Pakistan: Main report 2013 [Online]. Available from: http://disabilitycentre.lshtm.ac.uk/files/2013/04/Key-Informant-Child-Disability-Study-Main-Report.pdf [Accessed on 11 March 2019].

Maloni P K, Despres ER, Habbous J, Primmer AR, Slatten JB, Gibson BE, Landry MD (2010). Perceptions of disability among mothers of children with disability in Bangladesh: Implications for rehabilitation service delivery. Disability & Rehabilitation; 32(10): 845-854. https://doi.org/10.3109/09638280903326063 PMid:20131951

McConkey R, Mariga L, Braadland N, Mphole P (2000). Parents as trainers about disability in low income countries. International Journal of Disability, Development and Education; 47(3): 309-317. https://doi.org/10.1080/713671113

McNamara S, Moreton G (1995). Changing behaviour: Teaching children with emotional and behavioural difficulties in primary and secondary classrooms. London: David Fulton Publishers.

Mobarak R, Khan NZ, Munir S, Zaman SS, McConachie H (2000). Predictors of stress in mothers of children with cerebral palsy in Bangladesh." Journal of Pediatric Psychology; 25(6): 427-433. https://doi.org/10.1093/jpepsy/25.6.427 PMid:10980047

Nesbitt RC, Mackey S, Kuper H, Muhit M, Murthy GV (2012). Predictors of referral uptake in children with disabilities in Bangladesh- exploring barriers as a first step to improving referral provision. Disability and Rehabilitation; 34(13): 1089-95. https://doi.org/10.3109/09638288.2011.634943 PMid:22136387

Powell MA, Smith AB (2009). Children's participation rights in research. Childhood; 16(1): 124-142. https://doi.org/10.1177/0907568208101694

Schenk K, Williamson J (2009). Ethical approaches to gathering information from children and adolescents in international settings: guidelines and resources [Online]. Available from: https://www.popcouncil.org/uploads/pdfs/horizons/childrenethics.pdf [Accessed on 11 March 2019].

Singal N (2010). Doing disability research in a Southern context: Challenges and possibilities. Disability & Society; 25(4): 415-426. https://doi.org/10.1080/09687591003755807

United Nations (1989). The United Nations Convention on the Rights of the Child [Online]. Avaiable from: https://downloads.unicef.org.uk/wp-content/uploads/2010/05/UNCRC_united_nations_convention_on_the_rights_of_the_child.pdf?_ga=2.124888650.1947166161.1552302836-2025871646.1552302836 [Accessed on 11 March 2019].

United Nations (2006). Convention on the Rights of Persons with Disabilities (CRPD) [Online]. Available from: https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html [Accessed on 11 March 2019].

United Nations Children's Fund (2013). The state of the world's children: Children with disabilities [Online]. Available from: https://www.unicef.org/publications/files/SWCR2013_ENG_Lo_res_24_Apr_2013.pdf [Accessed on 11 March 2019].

World Health Organisation and World Bank (2011). World report on disability [Online]. Available from: https://www.who.int/disabilities/world_report/2011/report.pdf?ua=1 [Accessed on 11 March 2019].

Yousafzai AK, Filteau S, Wirz S (2003a). Feeding difficulties in disabled children leads to malnutrition: experience in an Indian slum. British Journal of Nutrition; 90(06): 1097-1106. https://doi.org/10.1079/BJN2003991 PMid:14641969

Yousafzai AK, Pagedar S, Wirz S, Filteau S (2003b). Beliefs about feeding practices and nutrition for children with disabilities among families in Dharavi, Mumbai. International Journal of Rehabilitation Research; 26(1): 33-41. https://doi.org/10.1097/00004356-200303000-00004 PMid:12601265

ORIGINAL RESEARCH

Understanding the Lives of Caregivers of Children with Cerebral Palsy in Rural Bangladesh: Use of Mixed Methods

Maria A Zuurmond[1]*, Ilias Mahmud[2], Sarah Polack[3], Jenny Evans[3]

1. London School of Hygiene and Tropical Medicine, UK
2. James P Grant School of Public Health, BRAC Institute of Global Health, BRAC University,Bangladesh
3. International Centre for Evidence in Disability (ICED), London School of Hygiene and Tropical Medicine, UK

ABSTRACT

Cerebral palsy is the most prevalent health condition linked to childhood disability in Bangladesh, yet support and rehabilitation for this group is limited. Understanding the impact of cerebral palsy at family level is important forthe development of appropriate interventions.

Purpose: *This study aims to explore the impact on the lives of caregivers of children with cerebral palsy.*

Methods: *The study used mixed methods. The PedsQL™Family Impact Questionnaire Module was administered to the main caregivers in 135 families with a child with cerebral palsy and 150 families that did not have a child with a disability, from the same villages. In-depth interviews and observations were undertaken with 10 families, and 2 focus group discussions were conducted with representatives from 14 parent/caregiver groups. The project was conducted from April 2011- April 2013. Data collection was from September 2011- Dec 2012.*

Results: *The mean overall and sub-scale PedsQL™ scores were significantly poorer ($p<0.001$) for caregivers of a child with cerebral palsy compared to scores from families that did not have a child with disability. Caregivers reported high levels of stress, anxiety, isolation, stigma, physical tiredness, and lack of time to complete everyday tasks. Knowledge and understanding about cerebral palsy was generally low.*

* **Corresponding Author:** Maria A Zuurmond, Research Fellow, London School of Hygiene and Tropical Medicine, UK. Email:maria.zuurmond@lshtm.ac.uk

Conclusion: *This study demonstrates the particular vulnerability of families of children with disabilities in resource-limited settings. It reveals the extent of the impact on the caregivers. Interventions therefore need to be holistic, addressing the well-being and empowerment of caregivers as well as children.*

Key words: *Disabilty, children with disabilities, quality of life, caregivers, Bangladesh*

INTRODUCTION

In 2005, the United Nations Children's Fund (UNICEF) estimated that 150 million children globally live with a disability. The majority live in low or middle- income countries (LMICS) where estimates of childhood disability prevalence range from 0.4% to 12.7% (UNICEF, 2005). It is well-documented that children with disabilities are often socially excluded, and frequently lack access to primary and rehabilitative healthcare and education (World Health Organisation and World Bank, 2011; UNICEF, 2013). The Convention on the Rights of the Child, and the Convention on the Rights of Persons with Disabilities direct governments to be responsible for ensuring that all children, irrespective of any disability, enjoy their rights without discrimination. Both of these Conventions also recognise the important role of the family, and the role of the State in supporting the family (United Nations, 1989; United Nations, 2006).

The Community Based Rehabilitation (CBR) guidelines emphasise the importance of empowerment of both the persons with a disability and their families (WHO, 2010). An increasing body of research highlights the importance of services that not only focus on the individual child but also meet the wider needs of the family, based on a good understanding of the experience of families that have a child with disability (Beresford, 1994; Balasundaram, 1995; Mobarak et al, 2000; Hartley et al, 2005; Raina et al, 2005).

Developing a Community-based Training Programme for Caregivers of Children with Cerebral Palsy in Bangladesh

A large-scale survey of childhood disability in Bangladesh, using the key informant methodology, estimated a prevalence of 0.9% of moderate or severe targeted impairments among children less than 18 years of age (Murthy et al, 2014). All children were assessed by a paediatrician in a camp setting, and cerebral palsy made up the greatest number within the cohort of children with

disabilities, with a prevalence of 0.37%, which translates into almost a quarter of a million children in Bangladesh (Murthy et al, 2014). Despite cerebral palsy accounting for more than a third of moderate and severe childhood disability, rehabilitative services available for these children are extremely limited. As a result of this survey, there was a commitment to develop a training programme for caregivers of children with cerebral palsy; a training programme which would be relevant and acceptable to families in the rural Bangladesh setting.

In Bangladesh, a small number of studies have sought to understand the experience of carers with a child with cerebral palsy (Mobarak et al, 2000; McConachie et al, 2001), and how best services might be delivered to families of children with cerebral palsy (McConachie et al, 2000; Maloni et al, 2010). One study explored the outcomes of young children with cerebral palsy and highlighted the very high mortality rates which exist (Khan et al, 1998). The key factors which contributed to the children's increased vulnerability included: living in a rural area, low income of the families, non-literate mothers, and least contact with disability rehabilitation services. A key recommendation from their research was the need for empowerment of the mother and the family, and the need for additional social and community support.

In September 2011, fourteen parent/caregiver groups were established by the Child Sight Foundation of Bangladesh, and caregivers were invited to attend a monthly training course.The training programme was developed through a process of action research over a 12-month period, and involved the participation of parents, children, community workers, and a multi-disciplinary team of therapists. There were several research components to the project which informed the development of the training programme. The purpose of this article is to present one component of the larger research project, namely, the findings of a mixed methods study conducted on the lives of the caregivers of children with cerebral palsy.

Objectives of the study

The objectives included:

(1) Understanding and assessing the family impact of caring for a child with cerebral palsy, and

(2) Understanding local knowledge and beliefs about the child's disability.

METHODS

Study Setting

The study was undertaken in 2 sub-districts of the Sirajganj district in Bangladesh -Kamarkhand and Ulla Para - over an 18-month period in 2012-2013. Bangladesh is a low-income country. The mainstream Government health systems do not include rehabilitation. Some rehabilitation is provided on a limited scale by the non-government organisations. During the study period there was no disability rehabilitation programme in the study area.

Study Sample

Participants in the study were the families of children with cerebral palsy who were identified during a large-scale survey in Bangladesh (Mactaggart and Murthy, 2013). A paediatrician had clinically assessed all the children as having a moderate or severe form of cerebral palsy. The study sample consisted of 153 families who had children with cerebral palsy aged 14 years or younger, who were invited to participate in the development of a new training programme for parents. At the same time, 150 normative families who did not have a child with a disability, were selected as a comparison group for the quality of life measure. The normative families were randomly selected from the same villages, and children were matched by age and gender.

A purposeful sample of 10 families was selected for in-depth interviews. Selection criteria included having children of different ages and a gender mix; the children were between 1-14 years of age, and consisted of 6 girls and 5 boys. One family had 2 children with cerebral palsy. This sample also included 2 families who were not regular attendees of the training programme, in order to better understand reasons for poor attendance. On completion of the 12-month intervention, 2 focus group discussions were also conducted with representatives of each of the 14 parent/caregiver support groups established.

Quantitative Data Collection

The authors used the 36-item PedsQL™Family Impact Questionnaire Module (Varni et al, 2004), a health-related quality of life questionnaire, which is designed to measure the impact of paediatric conditions on parents and the family. It measures parents' self-reported physical, emotional, social, and cognitive functioning, communication, and worry, as well as daily activities of the family,

and family relationships. This questionnaire was translated into Bengali using the standard forward and back-translation procedures, and piloted in the local setting before use.

The questionnaire was administered to the main caregiver in: a) the families with a child with cerebral palsy, and b) the normative families. Interviews were conducted by trained community workers, in the respondents' homes, before the participants started on the training programme.

Qualitative Data Collection

Interviews with the main caregiver were conducted over 3 to 5 visits to the family home during a 6-month to 1-year period, to explore a) the knowledge and understanding of cerebral palsy, and b) the impact of caring for a child with cerebral palsy.A topic guide was used to allow participants to tell their stories, underpinned by an interpretive phenomenological approach to the collection and interpretation of qualitative data (Creswell, 2009; Green and Thorogood, 2009). A half-day observation of the child in the household setting was conducted by the same researcher, and detailed notes were taken of the child and parent activities, and interactions related to the care and support of the child. Finally, at the end of the year-long training programme, 2 focus group discussions with the caregivers were conducted to explore their views on participating in the training programme.

Ethics

The research was approved by the Ethics Committee of the London School of Hygiene and Tropical Medicine and by the Child Sight Foundation of Bangladesh. Written informed consent was obtained from the participants. Privacy and confidentiality of the information provided was maintained throughout the study and in any subsequent publications.

Data Analysis

Quantitative

The quantitative data was analysed using Stata V11. Demographic characteristics (age, gender and family size) of the children with cerebral palsy and their matched controls were compared using Chi-squared test. The PedsQL™ sub-scale scores were converted into scores out of 100, with '0' as the worst possible score and '100' as the best score. T-tests were used to compare the PedsQLTM

scores between families with and without children with cerebral palsy, for each domain, separately as well as the overall total score.

Qualitative

The in-depth interviews and observations of children in the family setting were conducted by a local researcher. Interviews were in the local language. Detailed notes were taken wherever possible during the observation, and were written up thereafter. These notes were translated into English. The data from the interviews and observation notes were thematically analysed by one researcher, and also checked by a second bilingual researcher. NVivo 10, a qualitative software package, was used to manage the data analysis.

RESULTS

Out of the 153 families who had children with cerebral palsy, 135 (88%) completed the questionnaire, while 18 families were not included because they had moved away, were not contactable, or their children had died. The demographic characteristics of the sample are presented in Table 1. The children with and without cerebral palsy were similar in terms of age, gender and family size. The main caregiver was the mother in the majority of the families (90% of families with a child with cerebral palsy and 94% of normative families).

Table 1: Demographic characteristics of Children with Cerebral Palsy and the Normative Controls

	Child with Cerebral Palsy N (%)	Child from Normative Families N (%)	P-value
Child age (years)			
0-4	42 (31%)	57 (38%)	0.17
5-9	59 (43%)	68 (45%)	
10-14	43 (25%)	25 (17%)	
Child gender			
Male	81 (60%)	75 (50%)	0.09
Female	54 (40%)	75 (50%)	
Number of children in family aged <16years			
1	34 (25%)	38 (25%)	0.83
2	52 (38%)	61 (41%)	
3	37 (27%)	42 (28%)	
4+	12 (10%)	9 (6%)	

PedsQL™Family Impact Questionnaire

The overall mean PedsQL™ score for the main caregiver of a child with cerebral palsy was significantly lower (52.4) than the score for the main caregiver of the normative families (79.8, P<0.0001). This difference remained significant across the different age categories and gender of the children (see Table 2). The scores were significantly lower (p<0.0001) across all 8 domains for the caregiver of a child with a disability compared to normative families (Table 3).

Table 2: PedsQL™Family Impact Module scores stratified by Age and Gender

	Families with Child with Cerebral Palsy		Normative Families		P-value
	n	Mean (SD)	N	Mean (SD)	
All children	134	52.4 (10.3)	150	79.8 (9.5)	<0.0001
Age					
<5 years	42	51.5 (9.3)	57	80.4 (9.6)	<0.0001
5-9 years	59	52.9 (10.6)	68	79.4 (10.3)	<0.0001
10-14 years	33	52.5 (11.2)	25	79.6 (7.3)	<0.0001
Gender					
Male	81	52.5 (10.0)	75	79.4 (9.5)	<0.0001
Female	53	52.2 (10.8)	75	80.2 (9.6)	<0.0001

*One case had approx. 50% of QoL information missing so was set to missing

Table 3: Individual PedsQL™Family Impact scores across 8 Domains

	Families with Child with Cerebral Palsy		Normative Families		P-value
Domains	n	Mean (SD)	N	Mean (SD)	
Total Score	134	52.4 (10.3)	150	79.8 (9.5)	<0.0001
Physical Functioning	135	48.6 (14.7)	150	72.0 (12.5)	<0.0001
Emotional Functioning	135	25.1 (14.7)	150	78.1 (13.7)	<0.0001
Social Functioning	135	52.8 (22.4)	150	86.8 (12.6)	<0.0001
Cognitive Functioning	135	66.8 (18.2)	150	79.8 (13.2)	<0.0001
Communication	134	71.5 (15.8)	150	87.8 (11.0)	<0.0001
Worry	134	52.9 (13.2)	150	83.1 (11.9)	<0.0001
Daily Activities	134	38.9 (21.3)	150	72.1 (15.4)	<0.0001
Family Relationships	134	65.2 (20.0)	150	81.5 (13.8)	<0.0001

Qualitative Findings

In order to present the data coherently, aid interpretation of the mixed methods of data collection, and highlight areas of synergy with the quality of life data, the emerging themes were mapped, where relevant, under the PedsQL™domains.

In-depth interviews were conducted with 8 mothers, 1 grandmother and 1 father. There were totally 11 children with cerebral palsy, ranging in age from 1-14 years, and consisting of 5 boys and 6 girls. In fact, one family had 2 children with cerebral palsy. Eight of these families completed the full parent/caregiver training course, while two stopped attending part way through. Key issues which arose from the in-depth interviews and observational data helped to corroborate the findings of the quality of life questionnaire. More importantly, the qualitative data provided explanatory information for the low quality of life scores and how the issues were interconnected, which was invaluable for the development of the training programme.

Impact of Caring for the Child

a) Emotional functioning and worry

Emotional functioning and worry were two of the lowest quality of life scores for families. Correspondingly, high levels of worry and anxiety felt by the caregiver were two of the most common themes of the qualitative interviews. These feelings were commonly explained by the lack of support in caring for the child, physical exhaustion, very low levels of knowledge about cerebral palsy, and high levels of stigma related to having a disability.

> *"I face terrible problem as my child does not sleep at night. If I can't sleep at night, I feel really bad and tired. ..... I don't get assistance from anyone apart from the family members. A lot of my relatives and neighbours made remarks like ....'This is the result of their sins'.* [How do you feel when they make this kind of comments?] *I feel very bad, I feel like committing suicide. A few days ago I put my sister-in-law's child on the chair of my disabled child and she said very bad things to me and my child. She said, 'You want my child to become disabled like yours, that's why you put him on that chair.' My husband cried for a while after hearing such disappointing comments from his own sister"* (Mother of a 15-month-old son).

Anxiety and worry were commonly linked to concerns about the future of the child, including who would take care of the child later in life and whether the

child would be able to get married. The concern about marriage was expressed for both a male and a female child.

> *"I feel sad that my grandson is disabled. I am always worried about him. I don't worry about any of my children or other grandchildren. I take care of him now that I am alive, but what will happen to him after my death? Who will take as much care of him as me? I am always tense about these things"* (Grandmother of 12-year-old boy).

> *"I feel really bad that I am a mother of a disabled child, I feel pain deep inside. .....I also am very tense about her future. If this problem persists in the future, then there will be problem in education, mobility, and even in marriage"* (Mother of a 3-year-old girl).

b) Physical functioning and daily activities

Physical tiredness of the caregiver, combined with a lack of time to conduct everyday household chores, were key themes identified by the caregivers in the in-depth interviews. The mother was most often the sole carer, and also frequently combined this with livelihood activities. In some cases the child needed to be carried or supported by the caregiver throughout the day, which made it difficult to undertake even basic household activities.

> *"It becomes very difficult to take care of two disabled children. As the children are sick, it becomes problem for me to perform household work properly. Sometimes I have to skip cooking meal for once in the day. .....I usually take care of my children. But every member of my family takes care of them as well. But the children don't want to leave me for even a second. During cooking and other work I can't keep them close to me. And they cry during those times. That's why I can't work properly"* (Mother of two children with cerebral palsy -a 7-year-old daughter and a 5-year-old son).

In the two cases where the parents stopped attending the training course, the main reasons they gave for non-attendance were the lack of time because of competing household and income-generating activities, and also not having time to care for the child. The observations of the family also highlighted the obvious neglect of their children with cerebral palsy; it was observed that the children were very poorly cared for, lying in their own urine for several hours, while their parents worked nearby. In both families, it was observed that the fathers had no interaction with their son or daughter with disability when they came home,

and that it was the mothers who took on the caregiving role, but often in a very limited way.

In one family with a 9-year-old daughter, the mother talked about feeling exhausted in her caregiving role which she combined with income-generating work.

> *"I do pottery at house all day long. I have to cook food for all at home three times a day. My father-in-law is ill; I have to take care of him. During sharecropping, when the crops arrive at our house, I have to work on that. .....I have to look after my disabled child all the time. My husband sometimes helps me a bit in household work, but he does not help me with the child. He has no interest in the child. I feel stressed working so much at home. I never get the chance to relax at home. That's why I always feel weak. Now the child has grown up and she urinates and defecates lying down and sitting and it gets on her body. That's why I feel bad to clear her stool and urine"* (Mother of a 9-year-old daughter).

c) Social functioning, communication, and family support

Under the theme of family support, some caregivers described individual members of the family and neighbours who loved their child and were sympathetic and caring. However, the overall key themes were of isolation and lack of support; the difficulty in talking about their child's condition within the family, which was often compounded by the high levels of stigma surrounding having a child with a disability.

> *"Many of the neighbours and relatives still say bad things about my child and me. On the other hand some say good things. One of my sisters-in-law told me that this was the punishment of my sins. She hates my child and don't take her on lap. I feel very bad at these behaviours of others"* (Mother of a 3-year-old daughter).

Caregivers also mentioned that they were not aware of other children with disabilities within their own village, and that coming together to form a parent support group provided an invaluable opportunity to talk about their experience with other parents.

> *"There are many physically challenged children in our village. I did not know them before now* "(Focus Group Discussion-1).

d) Understanding and beliefs about cerebral palsy

Measuring levels of knowledge and understanding about cerebral palsy were not

a component of the quality of life measure, but the qualitative data highlights low levels of understanding about cerebral palsy, common myths held, and provides some explanation of the stigma felt by caregivers.

> *"I feel really sad as my child is a disabled person. What sin had I committed that Allah gave me a disabled child? I do most of her work although her father also helps me sometimes. I feel really bad about having to clean her up after toileting, as she is growing up and I can't do this forever. I feel really sad inside when I see other children from my neighbourhood are playing and running around"* (Mother of a 12-year-old daughter).

Parents commonly held several concurrent beliefs regarding the cause of their child's condition. The most common beliefs were that it was caused by bad spirits and/or the result of something they did or that happened to them during pregnancy. Despite several reported visits to healthcare providers, most families had not received any diagnosis for their child.The exceptions were two families who had sought treatment in Dhaka, the capital of Bangladesh, and had a good level of understanding about the condition.

Family members and neighbours commonly influenced the decision-making regarding treatment and care for the child.

> *"The traditional healer after examining the baby told me that while I conceived him, he was caught by spiritual forces..... usually we don't even believe in the treatment of the traditional healer, but took him [to a traditional spiritual healer].....after listening to the neighbours"*(Mother of a 15-month-old son).

All the interviewed parents mentioned visits to traditional healers for treatment of their child's condition. Caregivers commonly described having been to different types of traditional healers in their endless search for a cure for their child. This often involved various ceremonies to remove the bad spirits. One family mentioned having received a diagnosis of epilepsy (14% of the children with cerebral palsy in the original survey had been diagnosed with epilepsy) and that they had visited 20-30 traditional healers.

> *"The doctor gave her some medicines [for epilepsy], but I stopped giving the medicines to my child after two to three days. At that time I thought such a small child could not have epilepsy..... After I stopped giving her medicine, I took her to a traditional healer.....The healer told us that she was encountered by a bad spirit. The healer came to our house many times. He told us, if you sacrifice two pigeons, then your*

child will be fine. .....After I gave the pigeons, the healer applied witchcraft and gave her a talisman, but she did not recover.....After that I took her to almost 20-30 healers" (Father of a 9-year-old girl).

DISCUSSION

Cerebral palsy is one of the most prevalent conditions among children with disabilities in low and middle income countries. It is a neurological health condition, and children also often have associated impairments such as hearing, visual, and cognitive impairments (Donald et al, 2015; Donald et al, 2014). However, despite these wide ranging needs, the rehabilitation on offer for these children and their families, is scarce or non-existent in many low or middle-income countries, including Bangladesh, and there is a call for more home-based care of community approaches well-suited to low-resource settings (Donald et al, 2015; Donald et al, 2014).

This study was conducted to inform the development of a community-based parent programme. It found that caregivers of children with cerebral palsy in rural Bangladesh had significantly poorer quality of life compared to caregivers of children without disability. This is one of the very few studies to have explored the quality of life of families caring for a child with disability in comparison with matched families that did not have a child with disability, in a resource-limited setting. The quality of life findings provide evidence to support the argument that families of children with disabilities are amongst the most vulnerable and disadvantaged in already resource-poor communities. Historically, disability rehabilitation programmes focus only on the adult or child with disability, with little or no attention to the impact of disability on the wider family. Studies on the rehabilitation of children with cerebral palsy in Bangladesh and other LMICs have generally focussed on barriers to the uptake of services (Nesbitt et al, 2011;Bedford et al, 2013), or on evaluating approaches for improving a particular aspect of care (Khan et al, 1998; McConkey et al, 2000; Mobarak et al, 2000;Maloni et al, 2010). However this study, using the perspectives of the caregivers and a measure of their quality of life, highlights the importance of taking a more holistic view of the family's needs and priorities, particularly of mothers and other female caregivers such as grandmothers.

The current study supports the findings of a number of other studies in LMICs which have shown that the burden of care normally falls on a female member

of the family, and that high levels of stress and anxiety exist for the primary caregiver (Mobarak et al, 2000; Hartley et al, 2005). Other studies have also shown the role that the extended family plays in decision-making in relation to care of a child with disability (Hartley et al, 2005; Maloni et al, 2010; Bedford et al, 2013). Importantly, the present study provides additional details about the extent of the impact of caring on the primary caregivers, across a range of psychosocial domains; it also provides a richer picture of the complex lives of families who care for a child with disability. This understanding of the complexity of issues which influence the care of the child is crucial for planning relevant and acceptable family-centred community-based rehabilitation programmes in LMICS.

The isolation of the caregiver, and the seemingly limited support network and safety nets which exist to care for a child with disability in this rural Bangladesh setting, is a key finding with implications for development of an effective community-based intervention. In terms of the development of the parent training programme, the implication was the need to include home visits within the programme, which then facilitated an opportunity to engage with other members of the family and wider community. It was also imperative to ensure that the training included a focus on community-based rehabilitation. Consequently, an additional training module was developed on 'Disability in your community', to address wider issues around inclusion and stigma, access to disability funds, and access to education.

The study found low levels of knowledge about cerebral palsy, and traditional beliefs about aetiology associated with witchcraft were extremely strong in this rural area of Bangladesh. This often resulted in already very poor families spending considerable amounts of time and money seeking traditional cures. This supports findings from a number of other studies (Gona et al, 2006;World Health Organisation and World Bank, 2011;UNICEF, 2013). Engagement with traditional healers, as part of a wider community programme, may be beneficial and should be explored in future programmes.

Finally, the current study also highlights the value of using mixed methods. The qualitative research corroborated the findings of the quality of life scores, while also providing additional data on the underlying reasons and highlighting explanatory pathways in the dynamics of family and community life. Understanding these issues in greater depth is essential for informing the development of appropriate interventions at the community level.

Limitations

There were clear criteria for the purposeful sample of 10 families; however, the final choice was made by local project staff together with the local researcher, which may have resulted in the selection of families who were better known to project staff and more actively engaged in the training programme. The local Bangladeshi research assistant became familiar to the families over the course of the year, and this has benefits as well as possible limitations. Disadvantages include possible inhibition of the caregiver's responses (Morris, 1998). However, this was balanced against the level of trust between the researcher and the family, which meant that it was acceptable for him to enter the family home, and he was allowed to observe the child in the context of the family. For budgetary reasons, only a half-day observation of the families was planned. This was a short time period and may have given a biased representation of the daily activities and care of the child in the home setting.

CONCLUSION

The study findings show that any intervention for families of children with cerebral palsy needs to be holistic in its approach. There is a need to address the health and well-being of the caregiver, mainly the mother, as well as the child. Furthermore, it is imperative that interventions engage with the wider family and community. Poor communication in the family, high levels of stigma, and the need to build an effective support network for the families that have a child with disability, are all key issues which should be addressed in any community-based rehabilitation programme for children with cerebral palsy and their families.

ACKNOWLEDGEMENT

The authors are grateful to CBM International who funded the research and the development of the parent training manual for children with cerebral palsy, available free at http://disabilitycentre.lshtm.ac.uk/getting-to-know-cerebral-palsy/

The Child Sight Foundation (CSF) implemented this project in Bangladesh, led by the project manager Md.MonzurulAlam and supported by Md. Shafiqur Rahman.

Khaled Hossain Joarder interviewed all the children.

Note:

PedsQL™, Copyright © 1998 JW Varni, Ph.D. All rights reserved. For any information on the Questionnaire, information and permission to use: Mapi Research Trust, Lyon, France. E-mail: PROinformation@mapi-trust.org

Internet: www.proqolid.organd www.pedsql.org

REFERENCES

Balasundaram P (1995). Fostering pparental involvement. In: O'Toole, B. &McConkey, R. (eds.) Innovations in developing countries for people with disabilities. Lisieux Hall Publications. Available at http://www.eenet.org.uk/resources/docs/inno_dev_coun.php

Bedford J, Mackey S, Parvin A, Muhit M, Murthy G (2013). Reasons for non-uptake of referral: children with disabilities identified through the key informant method in Bangladesh. Disability & Rehabilitation; 35(25): 2164-70. http://dx.doi.org/10.3109/09638288.2013.770927 PMid:23480675

Beresford B A (1994). Resources and strategies: how parents cope with the care of a disabled child. Journal of Child Psychology and Psychiatry; 35(1): 171-209. http://dx.doi.org/10.1111/j.1469-7610.1994.tb01136.x PMid:8163627

Creswell J (2009). Mixed methods procedures. Research design: qualitative, quantitative, and mixed methods approaches. London: Sage

Donald KA, Kakooza AM, Wammanda RD, Mallewa M, Samia P, Babakir H, Bearden D, Majnemer A, Fehlings D, Shevell M (2015). Paediatric cerebral palsy in Africa: where are we? Journal of Child Neurology 30 (8): 963-971. http://dx.doi.org/10.1177/0883073814549245 PMid:25296926

Donald KA, Samia P, Kakooza-Mwesige A, Bearden D (2014). Paediatric cerebral palsy in Africa: a systematic review. Seminars in Paediatric Neurology; 21(1): 30-35. http://dx.doi.org/10.1016/j.spen.2014.01.001 PMid:24655402

Gona J, Hartley S, Newton C, Newton J (2006). Using participatory rural appraisal (PRA) in the identification of children with disabilities in rural Kilifi, Kenya. Rural and Remote Health; 6: 553 (online). PMid:16956314

Green J, Thorogood N (2009). Qualitative methods for health research. London: Sage

Hartley S, Ojwang V P, Bagawemu A, Ddamulira M, Chavuta A (2005). How do carers of disabled children cope? The Uganda perspective. Child: Care, Health and Development; 31(2): 167-180. http://dx.doi.org/10.1111/j.1365-2214.2004.00464.x PMid:15715696

Khan N Z, Ferdous S, Munir S, Huq S, McConachie H (1998). Mortality of urban and rural young children with cerebral palsy in Bangladesh. Developmental Medicine & Child Neurology, 40(11): 749-753. http://dx.doi.org/10.1111/j.1469-8749.1998.tb12343.x PMid:9881804

Mactaggart I, Murthy G (2013). The key informant child disability project in Bangladesh and Pakistan. Main Report. International Centre for Evidence in Disability, London School

of Hygiene and Tropical Medicine. Available at http://disabilitycentre.lshtm.ac.uk/key-publications/.

Maloni PK, Despres ER, Habbous J, Primmer AR, Slatten JB, Gibson BE , Landry MD (2010). Perceptions of disability among mothers of children with disability in Bangladesh: implications for rehabilitation service delivery. Disability & Rehabilitation; 32(10): 845-854 http://dx.doi.org/10.3109/09638280903326063 PMid:20131951

McConachie H, Huq S, Munir S, Ferdous S, Zaman S, Khan NZ (2000). A randomised controlled trial of alternative modes of service provision to young children with cerebral palsy in Bangladesh. The Journal of Paediatrics; 137(6): 769-776. http://dx.doi.org/10.1067/mpd.2000.110135 PMid:11113832

McConachie H, Huq S, Munir S, Kamrunnahar, Akhter N, Ferdous S, Khan NZ (2001). Difficulties for mothers in using an early intervention service for children with cerebral palsy in Bangladesh. Child: Care, Health and Development; 27(1): 1-12. http://dx.doi.org/10.1046/j.1365-2214.2001.00207.x PMid:11136337

McConkey R, Mariga L, Braadland N, Mphole P (2000). Parents as trainers about disability in low-income countries. International Journal of Disability, Development and Education; 47(3): 309-317. http://dx.doi.org/10.1080/713671113

Mobarak R, Khan NZ, Munir S, Zaman SS, McConachie H (2000). Predictors of stress in mothers of children with cerebral palsy in Bangladesh. Journal of Paediatric Psychology; 25(6): 427. http://dx.doi.org/10.1093/jpepsy/25.6.427 PMid:10980047

Morris J (1998). Don't leave us out: involving disabled children and young people with communication impairments. York: York publishing services.

Murthy GV, Mactaggart I, Mohammad M, Islam J, Noe C, Khan AI, Foster A, Smith A, Qureshi B, Gilbert C (2014). Assessing the prevalence of sensory and motor impairments in childhood in Bangladesh using key informants. Archives of Disease in Childhood; 99: 1103-1108. http://dx.doi.org/10.1136/archdischild-2014-305937 PMid:25005523 PMCid:PMC4251542

Nesbitt R, Mackey S, Kuper H, Muhit M, Murthy G (2011). Predictors of referral uptake in children with disabilities in Bangladesh - exploring barriers as a first step to improving referral provision. Disability and Rehabilitation; 34(13): 1089-1095. http://dx.doi.org/10.3109/09638288.2011.634943 PMid:22136387

Raina P, O'Donnell M, Rosenbaum P, Brehaut J, Walter S D, Russell D, Swinton M, Zhu B, Wood E (2005). The health and well-being of caregivers of children with cerebral palsy. Paediatrics; 115(6): e626-e636. http://dx.doi.org/10.1542/peds.2004-1689 PMid:15930188

United Nations (1989).The UN Convention on the Rights of the Child [Online]. Available: http://www.unicef.org.uk/UNICEFs-Work/Our-mission/UN-Convention/ [Accessed on 4 September 2013].

United Nations (2006).UN Charter on the Rights of Persons with Disabilities [Online]. Available: http://www.un.org/disabilities/default.asp?id=150 [Accessed on 4 Sept 2013].

United Nations Children's Fund - UNICEF (2005). The state of the world's children 2006: excluded and invisible. Available at http://www.unicef.org/sowc06/pdfs/sowc06_fullreport.pdf [Online]. New York: UNICEF. [Accessed on 5 September 2013].

United Nations Children's Fund - UNICEF (2013). State of the world's children: children with disabilities. Available at http://www.unicef.org/sowc2013/. New York: UNICEF.[Accessed on 5 September 2013].

Varni JW, Sherman SA, Burwinkle TM, Dickinson PE, Dixon P (2004). The PedsQL™ family impact module: preliminary reliability and validity. Health and Quality of Life Outcomes; 2(1): 55. http://dx.doi.org/10.1186/1477-7525-2-55 PMid:15450120 PMCid:PMC521692

World Health Organisation (2010).Community-based rehabilitation: CBR guidelines [Online]. Geneva: WHO. Available from: http://www.who.int/disabilities/cbr/guidelines/en/ [Accessed on 1 August 2013].

World Health Organisation & World Bank (2011). World report on disability [Online]. Geneva: WHO. Available from: http://www.who.int/disabilities/world_report/2011/en/index.html [Accessed on 19 December 2013].

Children with cerebral palsy in Ghana: malnutrition, feeding challenges, and caregiver quality of life

SARAH POLACK[1] | MEL ADAMS[2] | DAVID O'BANION[3] | MARJOLEIN BALTUSSEN[4] | SANDRA ASANTE[5] | MARKO KERAC[6,7] | MELISSA GLADSTONE[8] | MARIA ZUURMOND[1]

1 Department of Clinical Research, Faculty of Infectious and Tropical Diseases, London School of Hygiene & Tropical Medicine, London; **2** Independent Consultant in Disability and International Development, London, UK. **3** Department of Pediatrics, Emory University School of Medicine, Atlanta, GA, USA. **4** CBM, Accra; **5** Physiotherapy Department, Korle Bu Teaching Hospital, Accra, Ghana. **6** Department of Population Health, Faculty of Epidemiology and Public Health, London School of Hygiene & Tropical Medicine, London; **7** Leonard Cheshire Disability and Inclusive Development Centre, Department of Epidemiology and Child Health, University College London, London; **8** Department of Women and Children's Health Institute of Translational Medicine, University of Liverpool, Liverpool, UK.

Correspondence to Sarah Polack, Clinical Research Department, Faculty of Infectious and Tropical Diseases, London School of Hygiene & Tropical Medicine, Keppel Street, London WC1E 7HT, UK. E-mail: sarah.polack@lshtm.ac.uk

This article is commented on by Molyneux on page 855 of this issue.

PUBLICATION DATA
Accepted for publication 15th March 2018.
Published online 7th May 2018.

ABBREVIATIONS

MUAC	Mid-upper arm circumference
PedsQL	Pediatric Quality of Life Inventory
QoL	Quality of life
WHO	World Health Organization

AIM To assess feeding difficulties and nutritional status among children with cerebral palsy (CP) in Ghana, and whether severity of feeding difficulties and malnutrition are independently associated with caregiver quality of life (QoL).
METHOD This cross-sectional survey included 76 children with CP (18mo–12y) from four regions of Ghana. Severity of CP was classified using the Gross Motor Function Classification System and anthropometric measures were taken. Caregivers rated their QoL (using the Pediatric Quality of Life Inventory Family Impact Module) and difficulties with eight aspects of child feeding. Logistic regression analysis explored factors (socio-economic characteristics, severity of CP, and feeding difficulties) associated with being underweight. Linear regression was undertaken to assess the relationship between caregiver QoL and child malnutrition and feeding difficulties.
RESULTS Poor nutritional status was common: 65% of children aged under 5 years were categorized as underweight, 54% as stunted, and 58% as wasted. Reported difficulties with child's feeding were common and were associated with the child being underweight (odds ratio 10.7, 95% confidence interval 2.3–49.6) and poorer caregiver QoL ($p<0.001$). No association between caregiver QoL and nutritional status was evident.
INTERPRETATION Among rural, low resource populations in Ghana, there is a need for appropriate, accessible caregiver training and support around feeding practices of children with CP, to improve child nutritional status and caregiver well-being.

Cerebral palsy (CP) is a common cause of physical disability in children[1] and evidence suggests that children with CP are particularly vulnerable to malnutrition.[2] Reasons for this include physiological factors such as dysregulation of growth hormone secretion and muscle spasticity.[3] Feeding difficulties, including oral-motor impairments affecting chewing, food ingestion, and self-feeding, are common and often severe.[4,5] These difficulties may negatively impact the responsiveness of caregiver feeding practices, further reducing nutritional intake.[6] At the same time, malnutrition may exacerbate physical and cognitive functional limitations among children with CP through reduced muscle strength, lower immunity and cerebral development, and other negative impacts on general health.[7,8] The right to food is enshrined into various human rights charters; however the nutritional needs of children with disabilities are rarely addressed.[9] In rural, low resource settings additional challenges around limited availability of food and nutrition services are likely to be common. However, there is limited empirical information on the feeding and nutritional status and risk factors for malnutrition among children with CP in these settings, including in Ghana. This information is important for informing policies, programmes, and evidence based advocacy for children with CP and their families.

As well as increasing the risk of malnutrition, child feeding difficulties may negatively impact caregiver well-being.[10] Research has highlighted negative experiences and stress associated, for example, with drooling, choking, and the high level of assistance required to support children with CP.[10,11] However, while there is good theoretical rationale for an association, few studies have specifically explored the impact of feeding difficulties in children with CP on caregiver quality of life (QoL) particularly in rural low-income settings. It has been postulated that caregiver's recognition of their child being underweight may, itself,

 DOI: 10.1111/dmcn.13797 © 2018 Mac Keith Press

cause stress affecting QoL.[12] However, the independent relationship between malnutrition and caregiver QoL has not been well explored. This deserves attention in terms of the delivery and impact of appropriate interventions supporting both children with CP and their caregivers.

The objectives of this study were to: (1) estimate the prevalence of malnutrition and describe the feeding difficulties experienced by children with CP in rural Ghana; (2) assess possible risk factors for malnutrition in this population; and (3) assess whether feeding difficulties and nutritional status are independently associated with caregiver QoL.

What this paper adds

- Malnutrition is very common among children with cerebral palsy in this rural population in Ghana.
- Feeding difficulties in this population were strongly associated with being underweight.
- Feeding difficulties were associated with poorer caregiver quality of life (QoL).
- Child nutritional status was not associated with caregiver QoL.

METHOD

This article reports on a survey conducted as part of an evaluation to assess the impact of a caregiver training programme for carers of children with CP. More details on this programme and the evaluation are available in an online study report.[13] The study was conducted in eight sites across four regions in Ghana: Upper East (northern Ghana), Greater Accra, Brong Ahafo, and Ashanti (southern Ghana) regions.

Study participants

The study population included caregivers and children with CP who were identified for inclusion in the caregiver training programmes in eight different communities. They were primarily recruited from the community through databases of local community based rehabilitation programmes (n=46), as well as additional case findings through community leaders, mothers attending existing support groups, and other key informants (n=8). In addition, the records of physiotherapists from Agogo Presbyterian Hospital were reviewed and all children who had been diagnosed within the last 6 months and who had received less than two physiotherapy sessions were recruited (n=22). CP was identified as a diagnosis by a qualified clinician (developmental paediatrician or physiotherapist). Eligibility criteria to the training programme and research study were: confirmed diagnosis of CP and aged between 18 months and 12 years. This is the target age group for the caregiver training programme. Children may have had some previous physiotherapy but caregivers were excluded if they were already a member of a parent support group. The target for the evaluation study was to include eight training groups of eight to ten parents: recruitment efforts continued at each site until this size was reached. Each caregiver was invited to participate in the parent training programme as well as this research project. The data presented here were collected in May and June 2015, before the caregiver training programme was initiated.

Data collection

A structured questionnaire was used to collect data on the children (demographics, severity of CP, feeding difficulties, reported health status, and anthropometry) and their primary caregivers (socio-demographic and economic characteristics, and QoL). Data were collected by two interviewers who underwent three days of training. The questionnaire was pilot tested and verbally translated into three local languages.

Severity of CP was assessed using the Gross Motor Function Classification System (GMFCS).[14] To assess feeding difficulties, caregivers were asked to rate how often their child experienced difficulties with eight different domains of feeding (such as choking, eating enough) using a 5-point response scale ranging from 'never' to 'always' (questions available as Appendix S1, online supporting information). These questions were adapted from a previous study of children with CP in Bangladesh.[10]

Caregiver and family QoL was assessed using the 36-item Pediatric Quality of Life Inventory (PedsQL) Family Impact Module[15] which includes eight subscales: self-reported physical, emotional, social, and cognitive functioning, communication, worry daily activities and family relationships. The scale was translated into the three local languages following PedsQL linguistic validation guidelines.[16]

To assess for malnutrition, anthropometric measures were taken using standardized protocols adapted for use in the field. Where possible, standing height was measured for children 5 years and older and recumbent length was taken for children under 5 years. Knee height[17] (CLPR65 Anthropometric Caliper, MediForm, Oregon, USA) was recorded for all children to the nearest millimetre. Following World Health Organization (WHO) best-practice procedures,[18] height, length, and knee height measurements were obtained twice by two independent observers: the average was taken as the final measurement if they agreed to within less than 5mm, else both remeasured until agreement was achieved. Mid-upper arm circumference (MUAC) was recorded for all children (mm gradation MUAC tape, teaching aids at low cost). We recorded weight to the nearest 100g. Children who could not stand independently were first weighed together with their caregiver and then the weight of the caregiver alone was subtracted.

Statistical analysis

We regrouped GMFCS levels for analysis as follows: mild (GMFCS levels I and II), moderate (GMFCS level III), and severe (GMFCS levels IV and V). A composite feeding score was calculated from the eight feeding questions and divided into tertiles (least difficulties, middle, and greatest difficulties) for analysis. We assessed the internal consistency of this score by calculating Cronbach's alpha[19]

coefficients and item-total correlations. Principal components analysis was used to derive a socio-economic status index from poverty indicators including household building materials and asset ownership. The socio-economic status index was divided into tertiles for analysis.

Knee height was used as a proxy measure for children whose standing height (n=16) or recumbent height (n=3) were unobtainable. Knee height and laying length were plotted on a scatter graph and the line of best fit was used to predict missing height data. This approach was used in the absence of a validated method for converting knee height to standing height for children with CP. The Emergency Nutrition Assessment[20] and WHO Anthroplus software were used to calculate weight-for-age, height-for-age, and weight-for-height z-scores according to WHO growth standards. Children were considered to have malnutrition if they had z-scores between –2 and –3 and severe malnutrition if they had z-scores lower than –3.[21] The definition of wasting using MUAC was 115mm to 124mm and severe wasting was less than 115mm. Children with z-score values outside of the recommended range (>5 or 6, or <–5 or –6, depending on the measure) were excluded from the analysis as per standard guidelines – these being more likely due to error rather than real extreme values (n=6).[22]

Total and subscale PedsQL scores (calculated as the sum of the items over the number of items answered) were converted into scores out of 100.[15] We used the total scale score for analyses.

Multivariate logistic regression was undertaken to explore factors (socio-economic characteristics, severity of CP, and feeding difficulties) associated with being underweight. Underweight (defined for this analysis as weight-for-age z-score <2) was selected as the anthropometric indicator because it was considered the most robust measure, taking into account the difficulties measuring height for some children in this study population. Further, this has been identified in previous research as being a better predictor of mortality among children with CP compared to stunting and wasting.[23] Multivariate linear regression was used to explore the relationship between caregiver QoL with child malnutrition and feeding difficulties, adjusted for potential confounders (caregiver and child age, socio-economic status, region, and CP severity). For these analyses, QoL life data were transformed because the data were skewed. Square root transformation was selected as, using the 'ladder' command in Stata 14 (STATA Corp, College Station, TX, USA); this was found to best resemble a normal distribution. With consideration to the number of variables under study, we used p<0.01 as our cut-off for statistical significance.

Ethical considerations

Ethical approval was granted from ethics committees of London School of Hygiene & Tropical Medicine and The Noguchi Memorial Institute for Medical Research, College of Health Sciences, University of Ghana. Informed written or thumb-printed consent was sought from caregivers before data collection. All children with moderate or severe malnutrition were referred for follow-up.

RESULTS

Study population characteristics

Data were collected on 76 of the 77 children invited to participate (response rate 98%) (Table I). The majority of children were under 5 years (72%) and mean age was 3 years 9 months (95% confidence interval [CI] 3y 3mo–4y 6mo). There were 47% females in the sample. The majority of children had severe CP: 25% were classified as being in GMFCS level V, 28% in GMFCS level IV, 25% in GMFCS level III, 14% in GMFCS level II, and 8% in GMFCS level I. There were similar numbers of children from Northern (53%) and Southern (47%) Ghana and the distribution of CP severity did not differ by north/south. Households living in the north were more likely to be in the poorest quartile. Overall, of the 37 children of preschool/school age, only 10 were currently enrolled in school and 11 had ever attended school. Caregivers were nearly all female (97%) and the vast majority were mothers (80%) or grandparents (15%) of the children with CP for whom they were providing care. The majority of caregivers (61%) reported not having engaged in income generating activities in the past month and 43% had never attended school. While most caregivers were married (70%), just under half (49%) had fathers living in the same house as their affected child.

Child feeding

In terms of psychometric properties, for each item missing data was low (<1%), and maximum endorsement frequencies were below 80% which is considered acceptable.[24] The summary score showed good internal consistency with a Cronbach's alpha of 0.8 and item-total correlations above 0.7.[24]

Difficulties with the child's feeding were commonly reported (Fig. 1). More than half the caregivers reported their child experienced feeding problems at least 'sometimes' in all eight domains. Most caregivers (75%) reported their child 'always' needed help with feeding. Two-thirds of caregivers reported 'always' worrying about their child's feeding and 50% reported 'always' worrying their child was not eating enough. Similar findings were observed if children under 3 years, who may be expected because of their age to experience feeding difficulties, were excluded (data not presented). The median composite feeding score was 28.1 (interquartile range [IQR] 43.8) out of a highest possible score ('no difficulties') of 100.

Prevalence of malnutrition

A high proportion of the children in this sample were categorized as malnourished (Table II): 65% of children aged under 5 years were underweight, 54% were stunted, and 58% were wasted. Including the older children, 56% were stunted and 63% (<10y only) were underweight. All mean z-scores were below –1.8. We conducted a sensitivity analysis,

Table I: Socio-demographic characteristics of the children with cerebral palsy and their caregivers

	n	%
Child variables		
Sex		
Male	41	54
Female	35	46
Age group		
18mo–2y	31[a]	41
3–4y	23[a]	31
≥5y	21[a]	28
Region		
North	40	53
South	36	47
Cerebral palsy severity (GMFCS level)		
I (mild)	6	8
II (mild)	11	14
III (moderate	19	25
IV (severe)	21	28
V (severe)	19	25
Caregiver/household variables		
Age group		
<30y	23	30
30–39y	34	45
40–49y	15	20
≥50y	4	5
Relationship to child		
Mother	61	80
Father	1	1
Grandparent	11	15
Other	3	3
Worked in last month		
No	46	61
Yes	30	39
Marital status		
Married/living together	53	70
Divorced/separated	6	8
Widowed	6	8
Single	11	4
Ever attended school		
No	33	4
Yes	43	7
Highest level completed		
None	33	43
Primary	18	24
Junior High	13	17
Senior High	9	12
Tertiary	3	4

[a]Data were missing for one participant. GMFCS, Gross Motor Function Classification System.

excluding children with imputed height data, and the results were broadly similar. According to the MUAC measurements, only 21% of the sample were classified as wasted.

Factors associated with malnutrition

As shown in Table III, the risk of being underweight was significantly higher among children experiencing the greatest difficulties with feeding (i.e. in the highest feeding score tertile: odds ratio [OR] 10.7, 95% CI 2.3–49.6, p=0.002). Prevalence of underweight was higher among children with severe (71%) rather than mild (43%) CP, but this was of borderline significance (OR 3.6, 95% CI 0.9–13.6, p=0.06). No significant association was found with the other variables assessed. These results remained similar with adjustment for all variables included in Table III.

Caregiver and family QoL

In terms of psychometric properties of the PedsQL in this setting, the proportion of missing data was less than 1% and floor and ceiling effects were less than 80% for each summary score. Good total- and subscale internal consistency was demonstrated by high Cronbach's alpha values (>0.7) and item total correlations (range: 0.49–0.81). The only exception was the three-item communication subscale which had a Cronbach's alpha of 0.54.

Caregiver QoL scores in this study population were low: the median summary total score was 12.5 (IQR 20.8) out of a maximum score of 100 (highest QoL). Median summary scores for the subscales ranged from 0 (IQR 16.6) for daily activities to 16.7 (IQR 25.0) for physical functioning.

QoL scores were significantly lower among caregivers whose children had the greatest difficulties with feeding (median score 9.0) compared to those with least difficulties (24.6, p=0.004) even with adjustment for potential confounders (caregiver and child age, socio-economic status, north/south, and CP severity) (Table IV). QoL was similar for caregivers with a child with CP who was underweight (10.8) compared to caregivers whose child was not underweight (11.8, p=0.12).

DISCUSSION

The prevalence of malnutrition in this population of children with CP from rural Ghana was very high. Caregiver-reported difficulties with child's feeding were common and greater feeding difficulties were strongly associated with the child being underweight. Feeding difficulties, but not the presence of malnutrition, were also significantly associated with poorer caregiver QoL. This study contributes to the limited empirical data available on CP, malnutrition, and caregiver QoL in low- and middle-income countries.

Approximately two-thirds of this study population were malnourished and over a third were severely malnourished. The proportion of children underweight was almost six times the Ghana national average, according to the 2014 Demographic and Health Survey, which found 11% of children under 5 years were underweight and 2% severely underweight (ranging from 5.9%–10.5% and 0.7%–2.5% respectively in the four study regions).[25] Similarly 58% were wasted and 54% were stunted compared to the national average of 5% and 19% respectively (range across study regions: 1.3%–5.2% and 10.4%–17.2% respectively).[25]

These findings support previous studies highlighting that malnutrition is common among children with CP. The prevalence in the current study was higher than previously reported in both high- and low-income settings.[2] A recent study in Uganda, for example, which used the same growth reference standards, found that 52% of children with CP were malnourished, with underweight being the most common category at 42%.[26] The lower prevalence in the Uganda study may be partly attributed to the lower proportion of the study children with severe CP (53% in Ghana, 33% in Uganda). Furthermore, the children were

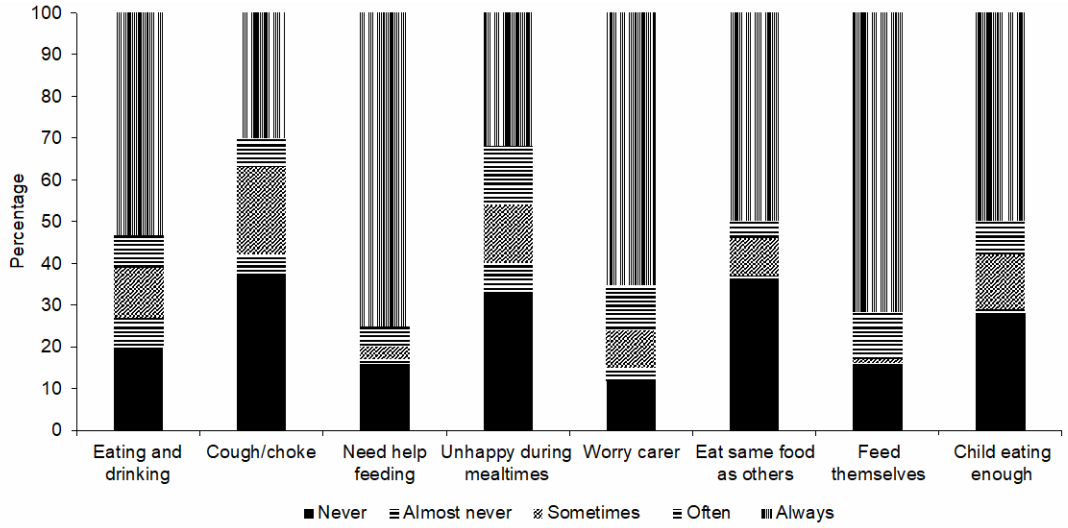


Figure 1: Caregiver-reported difficulties with child's feeding (caregivers were asked how often these aspects of feeding were a problem).

all attending a paediatric CP clinic and may be at lower risk of malnutrition.

The proportion of children with severe malnutrition based on low MUAC was considerably lower (20%) than that based on low weight-for-height z-score (57%). This discrepancy has been previously noted for children with CP.[26] MUAC, therefore, may not be sufficiently sensitive for this population. This is of concern, particularly considering MUAC is a preferred measure for admission to therapeutic and supplementary feeding programmes.[27] One possible reason for the discrepancy could be that children with CP mobilize more with their arms and thus MUAC is built up more than in other children, although as more than half of children were in the severe GMFCS category and would likely have weak spastic muscles this is unlikely to fully account for this discrepancy. However, given that all the other anthropometric indicators of malnutrition are strikingly high in this population and underlying disability is a risk factor for death among malnourished patients,[28] it could be argued that automatic referral of all children with CP for nutritional support is warranted. Our data thus support calls for closer links between nutrition and disability services; despite great potential for synergy and benefit there are currently too few referrals from disability services to feeding programmes (and vice versa).[29] Improved training on and inclusion of disability within nutrition programmes and health services more broadly needs to be prioritized. Further, early detection of CP accompanied by early intervention and regular monitoring with regards to nutritional status is needed to reduce the risk of malnutrition in this population.

Feeding difficulties were common among this population and children with the greatest feeding difficulties were significantly more likely to be underweight. Although this was a cross-sectional study, this finding supports other studies showing that difficulties with feeding are a key mechanism linking CP and malnutrition.[2]

Malnutrition was common even among children with mild and moderate CP and arguably higher than might be

Table II: Prevalence of malnutrition and mean z-scores

	All ages[a]		Children <5y	
	n	% (95% CI)	n	% (95% CI)
Weight for age				
'Normal' (WAZ≥–2)	24	37% (25.8–49.5)	17	35 (22.8–50.3)
Underweight (≥–3 to <2)	15	23% (14.2–35.1)	13	27 (16.1–41.8)
Severely underweight (<–3)	26	40% (28.5–52.6)	18	38 (24.6–52.4)
Mean WAZ (95% CI)	–2.6 (–3.0 to –2.2)		–2.5 (–3.0 to –2.1)	
Height for age				
'Normal' (HAZ≥–2)	29	41% (29.8–52.9)	24	46 (32.8–60.1)
Stunted (≥–3 to <2)	18	25% (16.4–37.0)	14	27 (16.4–40.9)
Severely stunted (<–3)	24	34% (23.6–45.8)	14	27 (16.4–40.9)
Mean HAZ (95% CI)	–2.3 (–2.6 to –1.9)		–2.1 (–2.5 to –1.7)	
Weight for height				
'Normal' (WHZ≥–2)			20	42 (28.3–56.4)
Wasted (≥–3 to <2)			16	33 (21.1–48.2)
Severely wasted (<–3)			12	25 (14.5–39.6)
Mean WHZ (95% CI)			–1.9 (–2.3 to –1.5)	
Mid-upper arm circumference				
'Normal' (≥125mm)			43	80 (66.4–88.9)
Wasted (115–124mm)			10	19 (10.1–31.2)
Severely wasted (<115mm)			1	1 (0–13)
Mean MUAC (95% CI)			143.0 (127.2–128.8)	

[a]Weight for age calculated for children under 10 years as per guidelines. WAZ, weight-for-age z-score; HAZ, height-for-age z-score; WHZ, weight-for-height z-score; MUAC, mid-upper arm circumference.

Table III: Association between underweight[a] and socio-demographic, clinical, and feeding variables among children aged under 10 years

	n	Number underweight[b] (%)	Age- and sex-adjusted odds ratios (95% CI)
Child variables			
Age			
18mo–2y	28	21 (75)	1.6 (0.4–5.8)
3–4y	20	10 (50)	0.6 (0.2–2.3)
≥5y	16	10 (63)	Reference
Sex			
Male	36	23 (65)	Reference
Female	28	18 (65)	1.1 (0.4–3.1)
Cerebral palsy severity			
Mild	14	6 (43)	Reference
Moderate	15	10 (67)	2.0 (0.4–8.9)
Severe	35	25 (71)	3.6 (0.9–13.6)
Serious health problem in past 12mo			
No	16	10 (63)	Reference
Yes	49	31 (63)	0.9 (0.3–3.1)
Feeding difficulties			
Least difficulties	17	6 (35)	Reference
Middle	22	13 (59)	3.0 (0.7–11.8)
Greatest difficulties	25	22 (89)	10.7 (2.3–49.6)[a]
Caregiver/household variables			
Age			
<30y	20	13 (65)	1.1 (0.3–5.0)
30–39y	30	20 (67)	1.6 (0.4–6.3)
>40y	14	8 (57)	Reference
Education			
None	27	19 (70)	Reference
Some	37	22 (59)	0.8 (0.3–2.3)
Socio-economic status			
Least poor	21	12 (57)	Reference
Medium	19	11 (53)	1.0 (0.3–3.6)
Poorest	23	18 (78)	2.7 (0.7–10.6)
North/South Ghana			
South	34	19 (56)	Reference
North	31	22 (71)	1.7 (0.6–5.1)

[a]Remained independently associated with being underweight with adjustment for all other variables (as potential confounders) included in the table. [b]Underweight is defined as any weight-for-age z-score <–2).

Table IV: Association between caregiver quality of life with feeding difficulties and malnutrition

	n	Median (SD) total QoL score	Adjusted[a] coefficient	Adjusted[a] *p*
Child variables				
Feeding difficulties				
Least difficulties	24	24.6 (32.6)	Reference[b]	Reference[b]
Middle	24	11.5 (20.8)	–1.06	0.06
Greatest difficulties	29	9.0 (1.04)	–1.86	0.004
Underweight				
Not underweight	24	10.8 (22.2)	Reference[c]	Reference[c]
Underweight	41	11.8 (18.8)	0.77	0.12

For these analyses, quality of life (QoL) life data were transformed (square root) because the data were skewed. [a]*p* value from linear regression analysis adjusted for caregiver and child age, socio-economic status, north/south, severity of cerebral palsy; [b]also adjusted for underweight; [c]also adjusted for feeding difficulties.

expected considering their level of physical functioning. This highlights a need for further research exploring factors influencing their nutritional status and for interventions to train and support caregivers in appropriate feeding practices. The lack of significant association between being underweight and severity of CP in this study may reflect the relatively small study sample, the broad categories of severity used as well as the high prevalence of malnutrition, as defined using WHO growth standards.

Greater feeding difficulties were associated with poorer caregiver QoL. This aligns with previous research showing that feeding difficulties can be stressful for carers as well as evidence that interventions which address feeding have a positive impact on QoL.[30] Possible reasons for this link include the emotional strain of feeding itself, associated with the child's motor deficit, drooling, choking, and the additional help required,[10] and concerns about the nutritional intake of the child. In addition, feeding can be very time-consuming both in terms of food preparation and actual mealtimes, particularly for children with greatest feeding difficulties. This, in turn, limits time available for other activities including income-generation which can have substantial economic consequences for families living in poverty, especially in this context where caregivers are most commonly females and in half of households where fathers were not living at home. The additional time and money required in food preparation and feeding has been noted previously as particularly challenging in low- and middle-income countries.[31]

The relationship with QoL may also be cyclical: evidence from other settings suggests that caregiver anxiety and depression is associated with more non-responsive or forceful feeding styles which may, in turn, contribute to the child's feeding difficulties. Further research, using qualitative methods, is needed to more fully understand the mechanisms linking feeding with QoL. Interestingly, caregiver QoL was not associated with their child's nutritional status. This suggests that the experience of feeding is the key issue for caregivers rather than their child's weight status. It may also reflect a historical perception of children with CP as being expected to be thin and small. The negative association between QoL and feeding difficulties highlights the need for caregiver support with mealtime challenges through community-based programmes and nutritional services.

Strengths and limitations

This is the first study to explore malnutrition, feeding difficulties, and caregiver QoL for children with CP in Ghana and contributes to the overall lack of empirical data on this topic from low-income countries. We used a standardized questionnaire and common anthropometric assessment methods.

There were some limitations. We did not include a control population without CP against which to compare findings. The sample size was relatively small and therefore some caution is warranted in interpreting the findings. We did not assess additional factors that may affect child nutritional status, such as dietary intake, which deserves attention in future studies. We did not use other classification systems

besides the GMFCS and our feeding difficulties scale, limiting the data available on the clinical features of our study population. Most children were identified through community programmes/case finding in rural areas and therefore findings may not be generalizable to wealthier, urban areas. This approach may also have resulted in over-representation of more severe cases of CP in our sample, which should be taken into consideration in interpretation of our findings. However, our data suggested that malnutrition was also common among children with mild CP and we adjusted for severity level in our multivariate analysis. Further, the inclusion of children identified in rural communities makes an important contribution to the literature as other similar studies in low- and middle-income countries have typically recruited children only from hospitals which may miss children from the most under-served areas.[26,32] This study found that feeding difficulties are common in this study population and are associated with undernutrition and poor caregiver QoL. However, it is not possible to determine the causal pathways between these variables, given the cross-sectional nature of this study and this deserves attention in future research.

Height measurement is challenging, particularly among children with CP who can have contractures and involuntary muscle spasms. In the absence of global guidelines we used knee height as a proxy for missing height data. In a sensitivity analysis, excluding those with imputed height, the findings remained essentially unchanged suggesting that this was not a major problem. Postural difficulties may have resulted in us overestimating height/length. This would have resulted in falsely higher levels of wasting and falsely lower stunting (in contrast to our population, in most nutritionally at-risk children, stunting is normally the most prevalent problem and wasting the least). Even if such measurement errors do explain part of our results, the general conclusion of high malnutrition still applies: weight for age would not be affected yet strongly suggests high levels of malnutrition. The finding, in this and previous studies,[2,26] that malnutrition is very common when defined using the WHO growth standards, requires some reflection as to whether these are the most appropriate growth charts to use for children with CP. Some previous studies have used CP growth reference curves. However, these are outdated, and in contrast to the WHO growth reference standards, they only describe how children do grow rather than how they should grow in ideal circumstances. Recent data have supported the use of WHO growth reference *z*-scores in assessing children with CP.[33] Finally, we acknowledge the discrepancy between acute malnutrition as assessed by MUAC and by weight-for-height *z*-score, which has also been observed in other populations.[34] A key future area for research is to identify which measure is most predictive of future risk and which is most appropriate and scalable in routine programming.[35] Low MUAC is the strongest predictor of mortality in many other populations and has significant advantages of simplicity, speed, and affordability and thus has the best potential for widespread use in resource-poor setting. But work is needed to explore whether the same advantages and same MUAC treatment thresholds apply to populations of children with disabilities.[36–38]

CONCLUSION

The prevalence of malnutrition among children with CP in Ghana was very high. Feeding difficulties were common and associated with both increased risk of malnutrition and poorer caregiver QoL. There is an urgent need to better link nutrition and disability services. This should include appropriate, accessible caregiver training, and support around feeding practices of their children with CP, both to improve child nutritional status and the well-being of their caregivers. Further research on anthropometric assessment for children with CP is also needed.

ACKNOWLEDGEMENTS

This study was funded by a grant from CBM International (https://www.cbm.org/). The authors have stated that they had no interests which might be perceived as posing a conflict or a bias.

SUPPORTING INFORMATION

The following additional material may be found online:

Appendix S1: Feeding questionnaire.

REFERENCES

1. Donald KA, Kakooza AM, Wammanda RD, et al. Pediatric cerebral palsy in Africa where are we? *J Child Neurol* 2014; **30**: 963–71.
2. Aggarwal S, Chadha R, Pathak R. Nutritional status and growth in children with cerebral palsy: a review. *Int J Med Sci Public Health* 2015; **4**: 737–44.
3. Stevenson RD, Hayes RP, Cater LV, Blackman JA. Clinical correlates of linear growth in children with cerebral palsy. *Dev Med Child Neurol* 1994; **36**: 135–42.
4. Gisel EG, Tessier MJ, Lapierre G, Seidman E, Drouin E, Filion G. Feeding management of children with severe cerebral palsy and eating impairment. *Phys Occup Ther Pediatr* 2003; **23**: 19–44.
5. Sullivan P, Lambert B, Rose M, Ford-Adams M, Johnson A, Griffiths P. Prevalence and severity of feeding and nutritional problems in children with neurological impairment: Oxford Feeding Study. *Dev Med Child Neurol* 2000; **42**: 674–80.
6. Black MM. Commentary: feeding problems: an ecological perspective. *J Pediatr Psychol* 1999; **24**: 217–19.
7. Dan B. Nutrition, brain function, and plasticity in cerebral palsy. *Dev Med Child Neurol* 2016; **58**: 890.
8. Kerac M, Postels DG, Mallewa M, et al. The interaction of malnutrition and neurologic disability in Africa. *Semin Pediatr Neurol* 2014; **21**: 42–9.
9. Groce NE, Kerac M, Farkas A, Schultink W, Bieler RB. Inclusive nutrition for children and adults with disabilities. *Lancet Glob Health* 2013; **1**: e180–1.
10. Adams M, Khan N, Begum SA, Wirz SL, Hesketh T, Pring TR. Feeding difficulties in children with cerebral palsy: low cost caregiver training in Dhaka, Bangladesh. *Child Care Health Dev* 2012; **38**: 878–88.
11. Mobarak R, Khan NZ, Munir S, Zaman SS, McConachie H. Predictors of stress in mothers of children with cerebral palsy in Bangladesh. *J Pediatr Psychol* 2000; **25**: 427–33.
12. Sullivan PB, Juszczak E, Lambert BR, Rose M, Ford-Adams ME, Johnson A. Impact of feeding problems on

nutritional intake and growth: Oxford Feeding Study II. *Dev Med Child Neurol* 2002; **44**: 461–7.

13. International Centre for Evidence in Disability Study Report. 2016. Evaluating the impact of a community-based parent training programme for children with Cerebral Palsy in Ghana. Available from: http://disabilitycentre.lshtm.ac.uk/files/2014/07/Ghanacountry-reportfinal.pdf (accessed 16 February 2018).

14. Wood E, Rosenbaum P. The gross motor function classification system for cerebral palsy: a study of reliability and stability over time. *Dev Med Child Neurol* 2000; **42**: 292–6.

15. Varni JW, Sherman SA, Burwinkle TM, Dickinson PE, Dixon P. The PedsQL family impact module: preliminary reliability and validity. *Health Qual Life Outcomes* 2004; **2**: 55.

16. Varni JW, Burwinkle TM, Seid M, Skarr D. The PedsQL 4.0 as a pediatric population health measure: feasibility, reliability, and validity. *Ambul Pediatr* 2003; **3**: 329–41.

17. Froehlich-Grobe K, Nary DE, Van Sciver A, Lee J, Little TD. Measuring height without a stadiometer: empirical investigation of four height estimates among wheelchair users. *Am J Phys Med Rehabil* 2011; **90**: 658–66.

18. WHO child growth standards: length/height-for-age, weight-for-age, weight-for-length, weight-forheight and body mass index-for-age: methods and development. (Technical Report). Available from: www.who.int/childgrowth/publications/technical_report_pub/en/index.html (accessed 15 March 2010).

19. Cronbach LJ. Coefficient alpha and the internal structure of tests. *Psychometrika* 1951; **16**: 297–334.

20. Emergency Nutrition Assessment (ENA). Software for standardized monitoring and assessment of relief and transitions (SMART). Available from: www.nutrisurvey.de/ena/ena.html (accessed 29 May 2016).

21. World Health Organization, UNICEF. WHO Child Growth Standards and the Identification of Severe Acute Malnutrition in Infants and Children: A Joint Statement by the World Health Organization and the United Nations Children's Fund. Geneva: World Health Organization. 2009.

22. Crowe S, Seal A, Grijalva-Eternod C, Kerac M. Effect of nutrition survey 'cleaning criteria' on estimates of malnutrition prevalence and disease burden: secondary data analysis. *PeerJ* 2014; **2**: e380.

23. Brooks J, Day S, Shavelle R, Strauss D. Low weight, morbidity, and mortality in children with cerebral palsy: new clinical growth charts. *Pediatrics* 2011; **128**: e299–307.

24. Lamping DL, Schroter S, Marquis P, Marrel A, Duprat-Lomon I, Sagnier PP. The community-acquired pneumonia symptom questionnaire: a new, patient-based outcome measure to evaluate symptoms in patients with community-acquired pneumonia. *Chest* 2002; **122**: 920–9.

25. Ghana Statistical Service, Ghana Health Service, ICF International. Ghana Demographic and Health Survey 2014. Rockville, Maryland, USA: Ghana Statistical Service, Ghana Health Service, ICF International, 2015.

26. Kakooza-Mwesige A, Tumwine JK, Eliasson AC, Namusoke HK, Forssberg H. Malnutrition is common in Ugandan children with cerebral palsy, particularly those over the age of five and those who had neonatal complications. *Acta Paediatr* 2015; **104**: 1259–68.

27. Briend A, Alvarez J-L, Avril N, et al. Low mid-upper arm circumference identifies children with a high risk of death who should be the priority target for treatment. *BMC Nutr* 2016; **2**: 63.

28. Kerac M, Bunn J, Chagaluka G, et al. Follow-up of post-discharge growth and mortality after treatment for severe acute malnutrition (FuSAM Study): a prospective cohort study. *PLoS ONE* 2014; **9**: e96030.

29. Groce N, Challenger E, Berman-Bieler R, et al. Malnutrition and disability: unexplored opportunities for collaboration. *Paediatr Int Child Health* 2014; **34**: 308–14.

30. Sullivan PB, Juszczak E, Bachlet AM, et al. Impact of gastrostomy tube feeding on the quality of life of carers of children with cerebral palsy. *Dev Med Child Neurol* 2004; **46**: 796–800.

31. Yousafzai AK, Pagedar S, Wirz S, Filteau S. Beliefs about feeding practices and nutrition for children with disabilities among families in Dharavi, Mumbai. *Int J Rehabil Res* 2003; **26**: 33–41.

32. Johnson A, Gambrah-Sampaney C, Khurana E, et al. Risk factors for malnutrition among children with cerebral palsy in Botswana. *Pediatr Neurol* 2017; **70**: 50–5.

33. Karagiozoglou-Lampoudi T, Daskalou E, Vargiami E, Zafeiriou D. Identification of feeding risk factors for impaired nutrition status in paediatric patients with cerebral palsy. *Acta Paediatr* 2012; **101**: 649–54.

34. Grellety E, Golden MH. Weight-for-height and mid-upper-arm circumference should be used independently to diagnose acute malnutrition: policy implications. *BMC Nutr* 2016; **2**: 1–17.

35. Myatt M, Khara T, Collins S. A review of methods to detect cases of severely malnourished children in the community for their admission into community-based therapeutic care programs. *Food Nutr Bull* 2006; **27** (Suppl. 3): S7–23.

36. ENN, SCUK, ACF, UNHCR. Mid upper arm circumference and weight-for-height z-score as indicators of severe acute malnutrition: a consultation of operational agencies and academic specialists to understand the evidence, identify knowledge gaps and to inform operational guidance. Final review paper 2012. Available from: http://files.ennonline.net/attachments/1398/muac-wfh-reportweb.pdf (accessed 3 February 2016).

37. Briend A, Marie B, Fontaine O, Garenne M. Mid-upper arm circumference and weight-for-height to identify high-risk malnourished under-five children. *Matern Child Nutr* 2012; **8**: 130–3.

38. Bhutta ZA, Berkley JA, Bandsma RHJ, Kerac M, Trehan I, Briend A. Severe childhood malnutrition. *Nat Rev Dis Primers* 2017; **3**: 17067.

RESUMEN

NIÑOS CON PARÁLISIS CEREBRAL EN GHANA: DESNUTRICIÓN, PROBLEMAS DE ALIMENTACIÓN Y CALIDAD DE VIDA DEL CUIDADOR

OBJETIVO Evaluar las dificultades de alimentación y el estado nutricional de los niños con parálisis cerebral (PC) en Ghana, y si la gravedad de las dificultades de alimentación y la desnutrición se asocian independientemente con la calidad de vida (CV) del cuidador.
MÉTODO Esta encuesta transversal incluyó 76 niños con parálisis cerebral (18 meses - 12 años) de cuatro regiones de Ghana. La gravedad de la PC se clasificó utilizando el Sistema de clasificación de la función motora gruesa y se tomaron medidas antropométricas. Los cuidadores calificaron su V (utilizando el Módulo de Impacto Familiar Pediátrico de Calidad de Vida ™) y las dificultades con ocho aspectos de la alimentación infantil. El análisis de regresión logística exploró factores (características socioeconómicas, severidad de la PC y dificultades de alimentación) asociados con la insuficiencia ponderal. Se realizó una regresión lineal para evaluar la relación entre la CV del cuidador y la desnutrición infantil y las dificultades de alimentación
RESULTADOS El estado nutricional deficiente era común: el 65% de los niños menores de 5 años se clasificaron como bajo peso, 54% como desnutrido y 58% como emaciado. Las dificultades informadas con la alimentación del niño fueron comunes y se asociaron con el bajo peso del niño (odds ratio: 10,7 intervalo de confianza del 95%: 2,3-49,6) y una CV del cuidador más pobre (p <0,001). No se observó ninguna asociación entre la CV del cuidador y el estado nutricional.
INTERPRETACIÓN Entre las poblaciones rurales de bajos recursos en Ghana, existe la necesidad de capacitación apropiada y accesible de cuidadores y apoyo en torno a las prácticas de alimentación de los niños con PC, para mejorar el estado nutricional del niño y el bienestar del cuidador.

RESUMO

CRIANÇAS COM PARALISIA CEREBRAL EM GANA: DESNUTRIÇÃO, DESAFIOS PARA ALIMENTAÇÃO, E QUALIDADE DE VIDA DO CUIDADOR

OBJETIVO Avaliar dificuldades de alimentação e o estado nutricional de crianças com paralisia cerebral (PC) em Gana, e se a severidade das dificuldades de alimentação e desnutrição são independentemente associadas com a qualidade de vida (QV) do cuidador.
MÉTODO Este estudo transversal incluiu 76 crianças com PC (18m-12a) de quatro regiões de Gana. A severidade da PC foi classificada usando-se o Sistema de Classificação da Função Motora Grossa e medidas antropométricas foram feitas. Os cuidadores pontuaram sua QV (usando o Módulo de Impacto Familiar do Inventário Pediátrico de Qualidade de vida® e dificuldades em oito aspectos da alimentação da criança. Análise de regressão logística explorou fatores (características sócio-econômicas, severidade da PC e dificuldades de alimentação) associados com presença de baixo peso. Regressão linear foi realizada para analisar a relação entre QV do cuidador com desnutrição e dificuldades de alimentação da criança.
RESULTADOS O pobre estado nutricional foi comum: 65% das crianças com idade abaixo de 5 anos foram caracterizadas como abaixo do peso, 54% como cronicamente desnutridas, e 58% como agudamente desnutridas. Dificuldades relatadas de alimentação da criança foram comuns e se associaram com a presença de baixo peso (odds ratio 10,7, intervalo de confiança 95% 2,3-49,6) e pior QV do cuidador (p<0,001). Nenhuma associação entre QV do cuidador e estado nutricional foi evidente.
INTERPRETAÇÃO Entre populações rurais, de baixos recursos em Gana, há necessidade de treinamento apropriado e acessível para cuidadores, e suporte sobre práticas de alimentação para crianças com PC, para melhorar o estado nutricional e bem estar do cuidador.

Received: 2 March 2018 | Revised: 24 July 2018 | Accepted: 26 July 2018

DOI: 10.1002/fsn3.788

ORIGINAL RESEARCH

WILEY Food Science & Nutrition Open Access

Improving nutritional status of children with Cerebral palsy: a qualitative study of caregiver experiences and community-based training in Ghana

Claudia Mary Donkor[1,2] | Jackie Lee[1] | Natasha Lelijveld[3,4] | Melanie Adams[5] | Marjolein Meande Baltussen[6] | Gifty Gyamah Nyante[7] | Marko Kerac[3,8] | Sarah Polack[1] | Maria Zuurmond[1]

[1]International Centre for Evidence in Disability, London School of Hygiene and Tropical Medicine, London, UK

[2]Rabito Health Services, Tema, Ghana

[3]Department of Population Health, London School of Hygiene and Tropical Medicine, London, UK

[4]No Wasted Lives, Action Against Hunger, UK

[5]Independent Consultant in Disability and International Development

[6]CBM International, Bensheim, Germany

[7]School of Biomedical and Allied Health Sciences, College of Health Sciences, University of Ghana, Accra, Ghana

[8]MARCH Centre, Faculty EPH, London School of Hygiene and Tropical Medicine, London, UK

Correspondence
Natasha Lelijveld, Department of Population Health, London School of Hygiene and Tropical Medicine, London, UK.
Email: natasha.lelijveld.11@ucl.ac.uk

Funding information
The development and implementation of the training program were funded by CBM.

Abstract

Background: Cerebral palsy (CP) is the most common childhood disability worldwide, and evidence shows that children with CP are at an increased risk of malnutrition due to feeding difficulties. This qualitative study explores caregiver experiences of feeding before and after a community-based training program in Ghana.

Methods: Thirteen caregivers of children with CP, who were severely undernourished, were interviewed at the start of the training program. Eleven of these were interviewed again after a year of monthly group trainings and home visits, which included guidance on feeding. Four additional caregivers were interviewed at end line. Interviews explored caregivers' mealtime experiences, as well as a 24-hr dietary recall and a structured feeding observation checklist. Children's nutritional status was assessed by anthropometry.

Results: Caregivers found mealtimes stressful due to time demands, messiness, and the pressure of providing enough quality food. They felt that the training program had helped reduced this stress and dietary recall data suggested some improved dietary quality. However, there was neither improvement nor deterioration in anthropometric status of the children.

Conclusion: Group trainings were welcomed by caregivers and notably reduced stress around feeding times. However, future work is needed in order to improve anthropometric outcomes, including, but not limited to, greater focus on nutritional requirements during caregiver training interventions. Therapeutic feeding programs must also be better utilized and need to be better equipped to care for this group of children, including deviating from standard admission and treatment protocols.

KEYWORDS
cerebral palsy, disability, feeding, Ghana, malnutrition

This is an open access article under the terms of the Creative Commons Attribution License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited.
© 2018 The Authors. *Food Science & Nutrition* published by Wiley Periodicals, Inc.

1 | INTRODUCTION

Cerebral palsy (CP) is a group of permanent neurological disorders affecting postural and movement development, attributed to nonprogressive disturbances in the developing fetal or infant brain (Donald, Samia, Kakooza-Mwesige, & Bearden, 2014). It is one of the most common childhood disabilities affecting between 1.5 and 4 children per 1000 live births globally (Division of Birth Defects and Developmental Disabilities 2017; Donald et al., 2014). CP is thought to be even more common and severe in low-income countries due to lack of access to early intervention and obstetric, neonatal, and rehabilitation services (Commey & Richardson, 1984; Groce et al., 2014). Despite this, relatively little is known about CP in African countries; there is especially limited evidence on population-specific caregiver experiences and the impact of interventions (Donald et al., 2014).

In addition to other comorbidities including epilepsy, and communication and behavior difficulties, neurological disability is associated with a greater risk of malnutrition (Eunson, 2012; Kerac et al., 2014). Greater nutrient requirements, increased nutrient loss, and decreased nutrient intake all contribute to this. In addition, malnutrition can exacerbate disability through reduced muscle strength, diminished immunity, and reduced cerebral development (Kerac et al., 2014). Prevalence of underweight (low weight-for-age) among children with CP was found to be 42% in Uganda and over 80% in Nigeria (Kakooza-Mwesige, Tumwine, Eliasson, Namusoke, & Forssberg, 2015; Ogunlesi, Ogundeyi, Ogunfowora, & Olowu, 2008), far exceeding the 30% prevalence that the WHO defines as being "very high" (WHO 2015). Given the increased risk of mortality associated with malnutrition, as well as long-term health implications, this issue needs to be urgently addressed.

As children with CP commonly have difficulties controlling their oral and facial muscles to chew and swallow, ensuring their adequate nutritional intake, as well as preventing aspiration, can be difficult for caregivers (Adams et al., 2011; Mobarak, Khan, Munir, Zaman, & McConachie, 2000). Few studies have explored in-depth caregiver's experiences of feeding difficulties in children with CP and interventions to address this. The study presented in this paper is part of a wider research project in Ghana, which assessed feeding difficulties and nutritional status among 76 children with CP and explored the impact of a 12-month, community-based, parent training program. The training program was based on the "Getting to Know Cerebral Palsy" (GTKCP) manual (http://disabilitycentre.lshtm.ac.uk/getting-to-know-cerebral-palsy/) and comprised of 11 modules delivered in group support sessions, including one on "Eating and Drinking." The program also included monthly home visits by training facilitators. Prior to implementation of the training, a baseline survey found that the prevalence of malnutrition was very high: 65% of children aged <5 years were categorized as underweight, 54% as stunted, and 58% as wasted. Reported difficulties with the child's feeding were common, and this was associated with the child being underweight (Odds Ratio 10.7 95% CI 2.3–49.6) and poorer caregiver quality of life ($p < 0.001$) (Polack et al., 2018; Zuurmond et al., 2018).

This article presents the findings of a qualitative study focussed on exploring caregivers' experiences of feeding, before and after the Ghana community-based training program was implemented, as well as anthropometric data and 24-hr dietary recall.

2 | METHODS

2.1 | Study design

This qualitative study was nested within a larger before/after study seeking to evaluate the impact of the community-based parent CP training program: GTKCP. Findings from this wider evaluation are published separately (Polack et al., 2018; Zuurmond et al., 2018). This qualitative study used semistructured interviews with primary caregivers of children with CP, both prior to ("baseline") and after 12 months of implementing the training manual ("end line"). In addition, data were collected using a 24-hr dietary recall, a feeding observation checklist, and anthropometric assessment of the children's nutritional status. These are presented to add context to these qualitative findings.

2.2 | Setting

The CP training program was implemented in eight geographical regions in Ghana. This qualitative study took place in four of those regions, selected based on feasibility of access: Agogo, Dodowa, Sunyani, and Techiman. The majority of interviews took place in participants' homes ($n = 14$). However, some interviews were conducted at the Physiotherapy Unit at Agogo Hospital, at caregivers' workplaces, or at a school. While efforts were made to ensure privacy, around half of the interviews had other children or adults present, with the interviewee's permission, due to the communal nature of home and work environments.

2.3 | Ethical approval

Ethical approvals were obtained from Noguchi Memorial Institute for Medical Research in Ghana (NMIMR-IRB CPN 053/14-15) and The London School of Hygiene and Tropical Medicine (LSHTM ref: 8905;10147;10880). Informed written or thumb-printed consent was obtained from each participant in advance of the research. Any child identified as wasted at baseline was referred to local therapeutic feeding programs.

2.4 | Research team and reflexivity

Interviews were conducted by CD who is a female, Ghanaian physician, fluent in both English and Twi languages and JL, an Asian Australian physiotherapist. Data analyses were conducted by CD, JL, and NL.

CD was introduced to participants at baseline interviews as a doctor and researcher. Interviews were conducted in Twi and/or

English, at the preference of the participant. Both CD and JL reflected on their occupational and cultural perceptions during daily reflective diary entries and during interpretation of interviewees' responses.

2.5 | Sampling

Participants were selected from caregivers of children (ages 1 to 16 years) with CP registered in a community-based rehabilitation program, who were invited to participate in the parent training program. A total of 15 caregivers of children who were identified, through anthropometric assessment (described below), as being moderately or severely malnourished were purposively selected for qualitative interview. No exclusions were made on severity of CP. Participants were invited to participate by phone or by home visit. In total, 13 of the 15 caregivers identified were available for interview.

The end-line sample consisted of 11 (out of the 13) caregivers from the baseline sample and four additional caregivers who were identified as having undernourished children during the course of the training program. In total, 16 children with CP were included as one caregiver was taking care of two children with CP. Two caregivers from the baseline sample were excluded, as one did not take part in the training program and the other was unavailable due to the hospitalization of her child. The end-line interviews were conducted 12 months after the baseline interviews, ensuring similar seasonal food availability (July 2015 and July 2016, respectively).

2.6 | Data collection

A semistructured interview guide was developed based on areas covered by the training program and included questions on positioning, utensils, and feeding improvement strategies. The end-line topic guide was similar to the baseline with additional questions about the perceived impact of the training on feeding. Interviews lasted approximately 40 min and were audio-recorded and later transcribed into English.

A 24-hr dietary recall questionnaire and a feeding observation were also conducted. The 24-hr dietary recall recorded feeding frequency, types of food, and food modification methods. The feeding observation used a structured observation checklist during observation of one meal. The interview guide, food recall questionnaire, and observation checklist were all based on tools developed for a study by Adams et al. in Bangladesh (Adams, 2009).

Child anthropometry was conducted as part of the wider research on all children included in the training program. Where possible, standing height was measured for children > 5 years and recumbent length was taken for children <5 years, both measured to nearest 0.1 cm. Knee height was recorded for all children to the nearest 0.1 cm using anthropometric calipers (CLPR65, MediForm, USA) (Froehlich-Grobe, Nary, Van Sciver, Lee, & Little, 2011). Mid-upper arm circumference (MUAC) was recorded for all children aged 6–59 months (MUAC tape, Teaching Aids at Low Cost). Weight was recorded to the nearest 0.1 kg. If it was not possible to measure a child's height or recumbent length, knee height was used as a proxy measure, based on the line of best fit on a scatter graph for children with complete data. Weight-for-age (WAZ) (children <10 years only), height-for-age (HAZ), and weight-for-height (WHZ) (children ≤5 years only) *z*-scores were calculated based on WHO growth standards, using WHO Anthroplus software. As per standard case definitions, children with z-scores ≤ −2 were defined as stunted (HAZ), wasted (WHZ), and underweight (WAZ), respectively. Children with MUAC <125 mm were also defined as wasted (WHO 2015).

The severity of each child's CP was assessed using the Gross Motor Function Classification System (GMFCS). Based on this system, scores one and two are defined as mild, three is moderate, and four and five are classified as severe CP (Rosenbaum, Palisano, Bartlett, Galuppi, & Russell, 2008).

2.7 | Analysis

A thematic analysis was conducted on the interview data; themes were discussed with coauthors, and key themes were triangulated with structured observations, the 24-hr dietary recall, and anthropometric data.

All the data were transcribed by CD and coded by CD, JL, and NL. Themes were derived both inductively and through predetermined areas of discussion, based on known feeding challenges from the literature, using NVivo 10 software. See Figure S1 for coding tree.

3 | RESULTS

3.1 | Sample description

Table 1 presents demographic characteristics of the caregivers and their children. A summary of the children's nutritional status is presented in Table 2 (individual data are presented in Table S1). The average age of the children at baseline was four years two months, ranging from 1 year 5 months to 11 years 11 months. The sample included 8 males and 11 females; although a range of CP severities was represented, the sample included mainly moderate-to-severe cerebral palsy. All caregivers were female except one; the majority were mothers, and they were all aged above 20 years.

3.2 | Structured observation of feeding

A short feeding observation was conducted for 11 children at baseline and 10 of the same children at end line, plus three additional children. Some form of oral-motor dysfunction was present in all the children in the sample; symptoms, either observed during the research or mentioned by caregivers, included difficulties in chewing and swallowing, presence of vomiting, drooling, choking, and coughing.

At baseline, one child was observed to self-feed and nine children were upright and supported during feeding. At end line, seven children were observed to self-feed (or partially self-feed) and eight children were upright and supported during feeding.

TABLE 1 Basic demographics of caregivers and children interviewed at baseline and/or end line

ID number	Caregiver relationship	Caregiver age (years)	Caregiver occupation	Child sex	Child age (baseline)	CP severity (GMFCS)	Time of interview
C1	Grandmother	40–60	Unemployed	Male	3 years 1 month	5	Baseline and end line
C2	Uncle	40–60	Unknown	Female	11 years 11 months	1	Baseline only
C3	Mother	30–40	Unemployed	Male	4 years 3 m	4	Baseline and end line
C4	Mother	30–40	Unemployed	Female	5 years 3 months	5	Baseline and end line
C5	Mother	40–60	Unemployed	Male	8 years 10 months	5	Baseline and end line
C6	Aunt	30–40	Unemployed	Female	1 year 5 months	4	Baseline and end line
C7	Mother	30–40	Employee	Male	2 years 6 months	5	Baseline and end line
C8	Grandmother	40–60	Unemployed	Female	5 years 1 month	3	Baseline only
C9	Mother	20–30	Employee	Female	3 years 6 months	4	Baseline and end line
C10	Mother	30–40	Farmer	Male	4 years 6 months	5	Baseline and end line
C11	Mother	30–40	Farmer	Female (a)	1 year 6 months	4	Baseline and end line
				Female (b)	6 years 4 months	1	Baseline and end line
C12	Mother	20–30	Unknown	Male	2 years 3 months	3	Baseline and end line
C13	Mother	30–40	Employed	Female	1 year 7 months	2	Baseline and end line
C14	Mother	30–40	Unemployed	Female	4 years 5 months	2	End line only
C15	Mother	20–30	Employee	Male	2 years 6 months	3	End line only
C16	Mother	30–40	Employee	Male	2 years 6 months	3	End line only
C17	Mother	40–60	Unemployed	Female	4 years 8 months	4	End line only

CP: cerebral palsy; GMFCS: Gross Motor Function Classification System.

The other children were fed reclined in the caregiver's lap. During baseline observation, it was noted that poor positioning often resulted in the oral spillage of fluids and food. Observations at end line demonstrated that positioning had improved, but one third of caregivers found it difficult to position their children, especially those with severe CP. Despite caregivers' efforts to position their child's body upright, the neck often remained extended.

At baseline, caregiver frustration during mealtime was commonly observed, manifesting as force-feeding in some instances. During end-line observations, none of the caregivers appeared frustrated or upset with their child; most were conversational or attentive to their child's eating and drinking.

TABLE 2 Summary of the nutritional status of children with CP at the time of baseline and end-line interviews

	Baseline (n = 18)	End line (n = 16)
Mean weight-for-height, z-score	−2.47	−2.24
Mean height-for-age, z-score	−2.13	−2.62
Mean MUAC (mm)	151	149
% Wasted	50%	50%
% Stunted	50%	50%

MUAC: mid-upper arm circumference; Stunted: height-for-age z-score ≤ −2; Wasted: weight-for-height z-score ≤ −2 or MUAC<125.

3.3 | 24-hr dietary recall

All caregivers were interviewed about their child's diet in the past 24 hr. Children were largely fed cereal-based porridge and some vegetables (Table 3). Despite most caregivers identifying fruit and protein sources (eggs/meat/fish) as healthy foods during the in-depth interviews, few provided these to their child with CP within the past 24 hr. Fish was the most common source of protein;

however, many children had inadequate or no protein in the diet, based on the food recall data. This was particularly so at baseline, with only 5/13 reporting any consumption of protein, while the endline survey suggested some improvement in protein intake (n = 12 consuming one or multiple sources).

3.4 | Semistructured interviews

Findings from the interviews are divided into pre- and posttraining. Several recurring themes have been identified, including length of mealtimes; modification of food; self-feeding; quality and quantity of food; and caregiver stress.

3.5 | Mealtimes at pretraining

3.5.1 | Length of mealtimes

This varied from 10 min to 3 hr. While there were examples of children feeding quickly, especially when the child liked the food, in many cases, long meal times were the norm, and some further lengthened by other comorbidities. It was reported by the mother of a 5-year-old girl that feeding was often prolonged due to recurrent seizures.

> It takes three minutes for her to finish chewing her food. If you speed up the mealtime, she coughs and chokes. One needs time and breaks in between. (referring to how long it takes to chew each morsel of food given) (C9)

3.5.2 | Modification of food

The majority of caregivers reported the need to modify the consistency of the food, making them softer or liquidized, to enable feeding. Others described preparing meals without pepper for their child as Ghanaian food typically has high levels of spice. Some caregivers reported giving the child only what he/she wanted to eat/drink to make feeding easier.

> He cannot chew meat or fish so I have to mash it into a powdery form before I add it to the food he is going to eat. (C3)

> I have to make the palm-nut soup thicker and make the rice softer before I feed her. (C4)

TABLE 3 Results of 24-hr dietary recall at baseline and end line

Food group (consumed in the past 24 hr)	Baseline		End line	
	n	%	*N*	%
Cereals and grains	13	100	16	100
Root vegetables	2	15	0	0
Vegetables	7	54	12	75
Fruit	0	0	0	0
Legumes	2	15	3	19
Eggs	1	8	5	31
Dairy	0	0	3	19
Nuts	1	8	7	44
Fish	4	31	8	50
Meat	0	0	1	6
Sugars	3	23	6	38
Breast milk	2	15	0	0
Vitamin supplements	0	0	1	6
Total sample	13	100	16	100

3.5.3 | Self-feeding

All but one of the carers perceived that their child was unable to self-feed. This was for a variety of reasons, including inability to use cutlery, messiness, and requiring positioning support.

> He is unable to eat like the other children so I have to feed him like a baby. (C3)

> He cannot eat by himself. He cannot hold cutlery so he needs to be fed. (C1)

Conversely, force-feeding was also deemed necessary by just over half of the caregivers at baseline (8/13). Some felt that this was required to ensure a nutritious or balanced diet; some felt that this was the only way to get their child to eat at all.

> When she is fed, the food has to be forced past her teeth and teeth pushed together by holding her jaws closed…food has to be pushed down her throat. (C4)

3.5.4 | Quality and quantity of food

Perceptions varied regarding the amount of food consumed. More than half of the respondents reported that their children had enough food at mealtimes. They also felt that they were able to provide some nutritious food each day. Conversely, half of participants felt their children needed more food, especially nutritious food.

> Yes! [She finishes everything on her plate]. Often, it is not enough! (C2)

> One needs patience when feeding him. If you look at his head-shaking during mealtimes as a sign to stop, you will be deceived and he will not have enough food to eat. (Referring to child's involuntary head movements) (C12)

3.5.5 | Caregiver stress

More than half of respondents expressed frustration or negative feelings about mealtimes. Most were concerned by the time-intensive and effort-demanding nature of mealtimes, which prevented them from engaging in other activities, including housekeeping and paid work. Their comments suggest that feeding is often physically exhausting as well as stressful.

> Taking care of her is stressful and strenuous. The whole day revolves around her and activities for her. By the time you go to bed, you are exhausted and have generalised body pains. You wake up exhausted too. (C9)

> Since it takes such a long time to feed him, I often do not have the time to do other things. I am unable to leave him and even go and work because of his condition. I need to work and support him and the other children but I just cannot. This makes me very unhappy. (C10)

Caregiver stress was related to all the above-identified feeding challenges, namely, the length of meal times, the need to modify food and prepare separate meals from those of the rest of the family, the perceived inability of children to feed themselves, the messiness caused during meals, and the pressure of providing enough and good quality food. Messiness was a particular concern for caregivers; it led to extra chores and was perceived as a factor in deterring others from helping caregivers with feeding.

> Because he is my son, I have more patience for him although sometimes I get angry with him as well. Sometimes when I get angry, I beat him. (C3)

> I am worried about the fact that he is not eating well in order to crawl and walk. I am unable to sleep at night from worrying about it. (C13)

> It is also hard and tiring feeding him. Sometimes, he is messy and I get covered with his food. When he is being fed, he spurts out the food and some lands on my face. It is very tiresome feeding him. (C3)

3.6 | Mealtimes posttraining

After attending the "Getting to Know Cerebral Palsy" program, caregivers reportedly felt less stressed about meal times and felt that the training had been helpful. Areas of the training particularly highlighted as helpful included positioning, self-feeding assistance, and suggestions on improving the variety of food groups in their child's diet. Although observations noted that positioning was still a challenge, multiple caregivers felt that the training had been helpful with regard to positioning their child:

> Initially [my daughter] was not able to eat or drink properly, but after the training there has been much improvement…Through the training we've understood what the condition is… we've learnt we need to be patient when giving [our children] the food, and also the types of food to give them… We've been able to apply [our] knowledge and things are much better C11a

> When he tilts the head, I help him to bring it forward because [I've] been told that if I don't do that, the food will not go down well (C12)

There were also positive feelings expressed about being able to connect with other caregivers of children with CP during the training:

> I felt encouraged, I was hopeful, because others would say 'my child started walking at age 4 or 5, so don't worry, your child is not there yet', so gradually, she will get to that age where she can walk. So I was very encouraged by their words (C13)

There was some evidence of improved dietary diversity based on the 24-hr dietary recall questionnaire (Table 3). Some caregivers also explained that they were able to give more diverse foods after having been given advice on appropriate modifications:

> At first he could only eat porridge and rice, but now he's able to eat all types of food. I have to modify some solids and for other foods like ampesi [boiled yam], I have to mash it a little bit before I give. (C5)

Despite some improvements and positive reflections from caregivers posttraining, caregivers still expressed a number of frustrations and concerns relating to feeding, and there was almost no evidence of improved nutritional status of the children based on anthropometry (Table 2).

3.6.1 | Length of mealtimes

Meal times still reportedly lasted between 10 min and 2 hr; therefore, some still being either too long or too short.

3.6.2 | Quality and quantity of food

The dietary recall data suggest some improvements in high-protein foods such as peanuts, eggs, and fish. However, there was still a notable lack of fruit in the diet, despite almost all caregivers identifying fruit as healthy when asked to give examples of healthy foods.

Half of caregivers at end line perceived that their child with CP ate less than other children;

> He doesn't eat the same quantity as other children his age and this is because of his condition (C10)

Some oral-motor dysfunction such as vomiting and drooling was interpreted as the child being full or not wanting their food, resulting in premature completion of meal times:

> Every time [I give] him porridge for breakfast, he starts spewing it out…That tells [me] that he's fed up with that meal (C3)

3.6.3 | Self-feeding

Self-feeding continued to be viewed quite negatively by caregivers, largely due to its association with mess. Even caregivers of children with moderate or mild CP identified self-feeding as a challenge.

> He'll put his hand in [the food] and just mess up the place. So [I] just [take my] time to do it. (C10)

3.6.4 | Caregiver stress

Although many caregivers reported reductions in mealtime stress, participants still voiced concerns about long mealtimes and financial strains. Even caregivers, who were relieved of some mealtime obligations by their child attending school, still felt anxious about whether their child was receiving adequate nutritional support during school hours.

Another source of concern was the lack of support received by caregivers from routine medical and nutrition services. The training intervention encouraged caregivers to seek nutrition support for acutely malnourished children. However, when visiting nutrition clinics, some were not referred for treatment, some were given advice that they felt was inappropriate, while others were referred for treatment but had difficulties attending appointments and did not receive follow-up. This disconnect with nutrition services seemed to be contributing to the limited care-seeking habits of caregivers:

> The nutritionist said for the child to be eating Plumpy'Nut raw, instead of having it mixed up in the food now. But with that, he doesn't eat it … [The nutritionist] didn't ask why he wasn't eating it. I didn't ask [for advice] either. (C13)

4 | DISCUSSION

This study identified six recurring themes which describe caregivers' experiences of feeding their children with CP: lengthy mealtimes; the need to modify food consistency; children's inability to self-feed; messiness at mealtimes; difficulty providing adequate quality and quantity of food; and caregiver stress, which was associated with all of the other experiences. These challenges mirror caregiver reports in previous studies (Adams et al., 2011; Sullivan et al., 2000).

After 12 months of the training program, caregivers felt that mealtimes were less stressful. Mealtimes can provide opportunities for caregivers and children to develop relationships. However, our baseline findings support studies in other settings; where for caregivers of children with CP, feeding is stressful or unenjoyable (Adams, 2009; Andrew & Sullivan, 2010; Gangil, Patwari, Aneja, Ahuja, & Anand, 2001). Furthermore, previous studies have found that stress can contribute to inappropriate feeding positions and methods, force-feeding, and verbal and physical abuse (Adams et al., 2011). The reduction in stress felt by caregivers in this study is therefore an important achievement of the training program and reinforces the value of caregiver training, as evidenced in previous studies with similarly positive outcomes (Adams et al., 2011).

In the follow-up feeding observations, the majority of children were supported upright during feeding and there was some small improvement in rates of self-feeding. Furthermore, although the 24-hr dietary recall found that the diet at baseline and end line consisted largely of cereal-based foods and some vegetables, there was an increase in protein content for some children following the training. Ongoing difficulties with positioning, especially head positioning, were still observed posttraining. This may have been due to a lack of uptake of supportive seating and an overreliance on lap-feeding. Caregivers, however, reported feeling better about positioning their child. They also reported feeling reassured by meeting other caregivers.

Despite the positive effects of the training program, it did not result in clear improvements in the unacceptably high prevalence of malnutrition in this group. While it is difficult to say how much of this reflects reduced disability-associated growth potential (Krick, Murphy-Miller, Zeger, & Weight, 1996), the magnitude of anthropometric deficit suggests that there is scope for further improved nutritional status in this group. Malnutrition is a known challenge for children with neuro-disabilities and children with CP are more likely to die young because of malnutrition (Colver, Fairhurst, & Pharoah, 2013). It is known that feeding difficulties in this population limit the ability to take in sufficient nutrition. It is also known that many have increased nutrient requirements, especially when comorbidities, such as seizures, are present (Kerac et al., 2014). Aspiration is also common in children with CP, which can lead to secondary chest infections, again resulting in higher nutritional needs (Tomkins & Watson, 1989).

This combination of issues makes it very difficult to provide enough nutrients to children with CP. In light of this, it is important to acknowledge the stabilization, rather than deterioration in nutritional status of the children involved in this training intervention, as a positive outcome. Further nutritional benefits may have been achieved with a greater emphasis given to the feeding component of the whole training package, especially attitudes toward self-feeding, for both direct caregivers and wider household members. A longer intervention may also have helped, given that it takes time for children to adapt to changes in feeding practices (Rosenbaum & Gorter, 2012). However, previous studies suggest that improving nutritional status in children with CP through caregiver training alone is a challenge. A similar training in Bangladesh also found minimal improvement in children's nutritional status as a result of caregiver training (Adams et al., 2011).

In high-income countries, children with CP regularly receive additional nutritional support via oral and nonoral means. However, children in this study who were referred to as mainstream therapeutic feeding services still showed no improvement in nutritional status and caregivers reported feeling largely dissatisfied with the support they received. Effective interventions to improve the nutritional status of children with CP in a low-income context, where children are relying on oral feeding alone, are urgently required. The nutrition sector needs to provide program staff with better guidance and training on how to manage children with neuro-disabilities. Further research is therefore needed to understand needs to nutrition sector staff and develop appropriate training.

Acute malnutrition is generally managed through community management (CMAM) whereby children identified as wasted are provided with "ready to use therapeutic food" (RUTF), a high-calorie peanut paste (Collins et al., 2006). These nutrition services are operated in the community with simple protocols; however, any child with a "complication" should be referred to an inpatient facility. Community implementers need to be better equipped with the knowledge to assess and refer children with CP. There may be an argument for blanket referral of all children with CP to nutrition services (Polack et al., 2018). These services need to be aware that deviation from standard protocols will likely be required when managing these cases, such as recognizing that children with CP may need to consume RUTF that has been modified in its consistency or to be provided with non-peanut-based RUTFs, which are less harmful to the lungs, if aspirated (Adams, 2009).

5 | RECOMMENDATIONS

Caregiver training interventions including specific training on feeding can improve mealtimes for both children and caregivers. However, we recommend that future training programs include a greater emphasis on the feeding component, given the high prevalence of malnutrition in this population. Specifically, greater emphasis should be placed on positioning, further encouragement for self-feeding, as well as improving dietary diversity. Involvement of other family members in the training program is also essential, especially in addressing physical exhaustion of caregivers and changing attitudes toward self-feeding and associated spillages. The need to seek additional nutritional support should also be stressed to caregivers. While effective nutrition interventions are still lacking in settings relying on oral feeding, the improved utilization and effectiveness of mainstream therapeutic feeding programs are recommended. Staff at therapeutic feeding programs need guidance on the treatment of malnutrition in children with CP and other neuro-disabilities, including the likely need to deviate from standard CMAM protocols.

6 | LIMITATIONS OF STUDY

This subsample of caregivers was only recruited in half of the intervention districts and therefore may not be representative of all views. In addition, there was a small difference in the sample size from baseline to end line, although the majority of caregivers (11) participated in both. Another limitation could be that the interviewers may have been perceived as associated with the training program team, and despite stressing in the introduction that they were neutral, this may have affected the participant's desire to feedback honestly about the training program or during feeding observations. Lastly, as in other nutritional studies of children with CP, anthropometry can be inaccurate due to arm muscle wasting and inability to stand for height measurements. However, this study used innovative anthropometric methods to perform nutritional assessment on as many of the sample as possible, including use of knee height to estimate standing height. It is hoped that this will inspire other nutrition studies to do the same (Lelijveld & Kerac, 2017).

7 | CONCLUSION

The findings of this study offer insight into mealtime challenges encountered by children with CP and their caregivers in Ghana, which are largely similar to those reported in studies from other countries. The results suggest that caregiver training can alleviate some of the difficulties faced by carers in relation to feeding their child with CP, and some of the stress associated with these. However, as in other studies where intervention involved caregiver training alone, there was no significant improvement in the children's anthropometric nutritional status. Besides attempts to further improve caregiver training, interventions need to go beyond this to address malnutrition. Better utilization and effectiveness of mainstream therapeutic feeding programs are necessary, including equipping these services to deviate from standard admission criteria and management protocols where necessary.

ACKNOWLEDGMENTS

The authors would like to firstly thank the families who gave their time to take part in the study. We would also like to acknowledge the dedicated contribution of the study team in Ghana as well as other advisors across the globe, especially Sandra Carsamer, David O'Banion, Jedidia Abanga, Anthony Adoboe, John Agana, and Kabiru Abass. Lastly, we thank the Christian Blind Mission (CBM) who generously funded the creation and implementation of the "Getting to Know Cerebral Palsy" Training Programme.

CONFLICT OF INTEREST

Authors declare no conflict of interest.

ETHICAL STATEMENT

The study's protocols and procedures were ethically reviewed and approved by two recognized ethical bodies: Noguchi Memorial Institute for Medical Research in Ghana (NMIMR-IRB CPN 053/14-15) and The London School of Hygiene and Tropical Medicine (LSHTM ref: 8905;10147;10880). Informed written or thumb-printed consent was obtained from each participant in advance of the research.

ORCID

Natasha Lelijveld http://orcid.org/0000-0002-8452-0198

REFERENCES

Adams, M. S. (2009). *The management of feeding difficulties in children with cerebral palsy in Bangladesh*. UCL (University College London).

Adams, M., Khan, N., Begum, S., Wirz, S., Hesketh, T., & Pring, T. (2011). Feeding difficulties in children with cerebral palsy: low cost caregiver training in Dhaka, Bangladesh. *Child: Care, Health and Development*, *38*(6), 878–888. https://doi.org/10.1111/j.1365-2214.2011.01327

Andrew, M. J., & Sullivan, P. B. (2010). Feeding difficulties in disabled children. *Paediatrics and Child Health*, *20*(7), 321–326. https://doi.org/10.1016/j.paed.2010.02.005

Collins, S., Dent, N., Binns, P., Bahwere, P., Sadler, K., & Hallam, A. (2006). Management of severe acute malnutrition in children. *The Lancet*, *368*(9551), 1992–2000. https://doi.org/10.1016/S0140-6736(06)69443-9

Colver, A., Fairhurst, C., & Pharoah, P. O. D. (2013). Cerebral palsy. *The Lancet*, *383*(9924), 1240–1249.

Commey, J., & Richardson, J. (1984). Cerebral palsy in Ghanaian children. *West African Journal of Medicine*, *3*, 157–163.

Division of Birth Defects and Developmental Disabilities, N. C. o. B. D. a. D. D. (2017). Data and Statistics for Cerebral Palsy. Available from: https://www.cdc.gov/ncbddd/cp/data.html [last accessed 18 July 2017].

Donald, K. A., Samia, P., Kakooza-Mwesige, A., & Bearden, D. (2014). *Pediatric cerebral palsy in Africa: a systematic review*. Seminars in pediatric neurology: Elsevier.

Eunson, P. (2012). Aetiology and epidemiology of cerebral palsy. *Paediatrics and Child Health*, *22*(9), 361–366. https://doi.org/10.1016/j.paed.2012.05.008

Froehlich-Grobe, K., Nary, D. E., Van Sciver, A., Lee, J., & Little, T. D. (2011). Measuring height without a stadiometer: empirical investigation of four height estimates among wheelchair users. *American Journal of Physical Medicine & Rehabilitation/Association of Academic Physiatrists*, *90*(8), 658. https://doi.org/10.1097/PHM.0b013e31821f6eb2

Gangil, A., Patwari, A., Aneja, S., Ahuja, B., & Anand, V. (2001). Feeding problems in children with cerebral palsy. *Indian Pediatrics*, *38*(8), 839–846.

Groce, N., Challenger, E., Berman-Bieler, R., Farkas, A., Yilmaz, N., Schultink, W., … Kerac, M. (2014). Malnutrition and disability: unexplored opportunities for collaboration. *Paediatrics and International Child Health*, *34*(4), 308–314. https://doi.org/10.1179/2046905514Y.0000000156

Kakooza-Mwesige, A., Tumwine, J. K., Eliasson, A. C., Namusoke, H. K., & Forssberg, H. (2015). Malnutrition is common in Ugandan children with cerebral palsy, particularly those over the age of five and those who had neonatal complications. *Acta Paediatrica*, *104*(12), 1259–1268. https://doi.org/10.1111/apa.13089

Kerac, M., Postels, D. G., Mallewa, M., Jalloh, A. A., Voskuijl, W. P., Groce, N., … Molyneux, E. (2014). *The interaction of malnutrition and neurologic disability in Africa*. Seminars in pediatric neurology: Elsevier.

Krick, J., Murphy-Miller, P., Zeger, S., & Weight, E (1996). Pattern of growth in children with cerebral palsy. *Journal of the American Dietetic Association*, *96*(7), 680–685. https://doi.org/10.1016/S0002-8223(96)00188-5

Lelijveld, N., & Kerac, M. (2017). A holistic approach to malnutrition follow-up care. *Journal of Public Health and Emergency*, *1*(4).

Mobarak, R., Khan, N. Z., Munir, S., Zaman, S. S., & McConachie, H. (2000). Predictors of stress in mothers of children with cerebral palsy in Bangladesh. *Journal of Pediatric Psychology*, *25*(6), 427–433. https://doi.org/10.1093/jpepsy/25.6.427

Ogunlesi, T., Ogundeyi, M., Ogunfowora, O., & Olowu, A. (2008). Socio-clinical issues in cerebral palsy in Sagamu, Nigeria. *South African Journal of Child Health*, *2*(3).

Polack, S., Adams, M., O'banion, D., Baltussen, M., Asante, S., Kerac, M., … Zuurmond, M. (2018). Children with cerebral palsy in Ghana: malnutrition, feeding challenges, and caregiver quality of life. *Developmental Medicine & Child Neurology*, *60*(9), 914–921. https://doi.org/10.1111/dmcn.13797

Rosenbaum, P., & Gorter, J. (2012). The 'F-words' in childhood disability: I swear this is how we should think!. *Child: Care, Health and Development*, *38*(4), 457–463.

Rosenbaum, P. L., Palisano, R. J., Bartlett, D. J., Galuppi, B. E., & Russell, D. J. (2008). Development of the gross motor function classification system for cerebral palsy. *Developmental Medicine & Child Neurology*, *50*(4), 249–253. https://doi.org/10.1111/j.1469-8749.2008.02045.x

Sullivan, P., Lambert, B., Rose, M., Ford-Adams, M., Johnson, A., & Griffiths, P. (2000). Prevalence and severity of feeding and nutritional problems in children with neurological impairment: Oxford Feeding Study. *Developmental Medicine and Child Neurology*, *42*(10), 674–680. https://doi.org/10.1017/S0012162200001249

Tomkins, A., & Watson, F. (1989). Malnutrition and infection: a review, ACC/Subcommittee on Nutrition.

WHO. (2015). Global Database on Child Growth and Malnutrition. Retrieved 31/10/2015, from http://www.who.int/nutgrowthdb/about/introduction/en/index5.html.>

Zuurmond, M., O'Banion, D., Gladstone, M., Carsamar, S., Kerac, M., Baltussen, M., … Polack, S. (2018). Evaluating the impact of a community-based parent training programme for children with cerebral palsy in Ghana. *PLoS ONE*. https://doi.org/10.1371/journal.pone.0202096 In press.

SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of the article.

How to cite this article: Donkor CM, Lee J, Lelijveld N, et al. Improving nutritional status of children with Cerebral palsy: a qualitative study of caregiver experiences and community-based training in Ghana. *Food Sci Nutr*. 2019;7:35–43. https://doi.org/10.1002/fsn3.788

References

These are a full set of references from all chapters, excluding the published papers.

Ab Rahman, A., Mohamad, N., Imran, M. K., Ibrahim, W. P. W., Othman, A., Aziz, A. A., Harith, S., Ibrahim, M. I., Ariffin, N. H. & Van Rostenberghe, H. 2011. A preliminary study on the reliability of the Malay version of PedsQL™ Family Impact Module among caregivers of children with disabilities in Kelantan, Malaysia. *The Malaysian journal of medical sciences: MJMS,* 18**,** 63.

Abberley, P. 1987. The concept of oppression and the development of a social theory of disability. *Disability, handicap & society,* 2**,** 5-19.

Aboud, F. E. & Yousafzai, A. K. 2015. Global health and development in early childhood. *Annual review of psychology,* 66**,** 433-457.

Adams, M., Khan, N., Begum, S., Wirz, S., Hesketh, T. & Pring, T. 2011. Feeding difficulties in children with cerebral palsy: low cost caregiver training in Dhaka, Bangladesh. *Child: care, health and development,* 38**,** 878-888.

Al-Krenawi, A., Graham, J. R. & Al Gharaibeh, F. 2011. The impact of intellectual disability, caregiver burden, family functioning, marital quality, and sense of coherence. *Disability & Society,* 26**,** 139-150.

Alaee, N., Shahboulaghi, F. M., Khankeh, H. & Kermanshahi, S. M. K. 2015. Psychosocial challenges for parents of children with cerebral palsy: A qualitative study. *Journal of Child and Family Studies,* 24**,** 2147-2154.

Aldersey, H. M. 2012. Family perceptions of intellectual disability: Understanding and support in Dar es Salaam. *African journal of disability,* 1.

Aldersey, H. M., Kavira, S., Kiasimbua, J., Lokako, W., Miaka, P. & Monte, L. 2018. Stigma experienced by families with members with intellectual disabilities in Kinshasa, Democratic Republic of the Congo. *Intervention,* 16**,** 119-128.

Ali, A., Hassiotis, A., Strydom, A. & King, M. 2012. Self stigma in people with intellectual disabilities and courtesy stigma in family carers: A systematic review. *Research in developmental disabilities,* 33**,** 2122-2140.

Allport, G. W., Clark, K. & Pettigrew, T. 1954. *The nature of prejudice,* Oxford, Addison-Wesley Publishing.

Andrews, F. M. & Withey, S. B. 1976. Social indicators of well-being: Americans' perception of quality of life. *The Management Group*.

Awedoba, A. K. & Denham, A. R. 2014. The Perception of abnormality in Kasena and Nankani infants: clarifying infanticide in northern Ghana. *Ghana Studies,* 15-16**,** 41- 68.

Badas, Ekjut, Women and Children First & Ucl. 2011. *Community Mobilisation through women's groups to Improve the health of mothers and babies* [Online]. Badas/Ekjut/Women and Children First /UCL. Available: https://www.womenandchildrenfirst.org.uk/.

Balasundaram, P. 1995. Fostering Parental Involvement. *In:* O'TOOLE, B. & MCCONKEY, R. (eds.) *Innovations in developing countries for people with disabilities. Available at http://www.eenet.org.uk/resources/docs/inno_dev_coun.php.* Lisieux Hall Publications.

Banks, L. M., Kelly, S. A., Kyegombe, N., Kuper, H. & Devries, K. 2017a. "If he could speak, he would be able to point out who does those things to him": Experiences of violence and access to child protection among children with disabilities in Uganda and Malawi. *PLoS one,* 12**,** e0183736.

Banks, L. M., Kuper, H. & Polack, S. 2017b. Poverty and disability in low-and middle-income countries: A systematic review. *PloS one,* 12**,** e0189996.

Banks, L. M., Mearkle, R., Mactaggart, I., Walsham, M., Kuper, H. & Blanchet, K. 2017c. Disability and social protection programmes in low-and middle-income countries: a systematic review. *Oxford Development Studies,* 45**,** 223-239.
Banks, L. M. & Polack, S. 2014. The economic costs of exclusion and gains of inclusion of people with disabilities. *CBM, International Centre for Evidence in Disability and London School of Hygiene & Tropical Medicine*.
Barlindhaug, G., Umar, E., Wazakili, M. & Emaus, N. 2016. Living with disabled children in Malawi: Challenges and rewards. *African Journal of Disability,* 5**,** 254.
Barnes, C. 2012. The social model of disability: Valuable or irrelevant. *The Routledge handbook of disability studies***,** 12-29.
Baskind, R. & Birbeck, G. L. 2005. Epilepsy-associated stigma in sub-Saharan Africa: the social landscape of a disease. *Epilepsy & Behavior,* 7**,** 68-73.
Batliwala, S. 2015. Engaging with Empowerment: An intellectual and experiential journey. New Delhi: Women Unlimited.
Bedford, J., Mackey, S., Parvin, A., Muhit, M. & Murthy, G. 2013. Reasons for non-uptake of referral: children with disabilities identified through the Key Informant Method in Bangladesh. *Disability & Rehabilitation***,** 1-7.
Belsky, J. 1984. The determinants of parenting: A process model. *Child development***,** 83-96.
Beresford, B. A. 1994. Resources and strategies: How parents cope with the care of a disabled child. *Journal of Child Psychology and Psychiatry,* 35**,** 171-209.
Berghs, M. 2017. Practices and discourses of ubuntu: Implications for an African model of disability? *African Journal of Disability (Online),* 6**,** 1-8.
Berman, R. C. & Tyyskä, V. 2011. A critical reflection on the use of translators/interpreters in a qualitative cross-language research project. *International Journal of Qualitative Methods,* 10**,** 178-190.
Berthoud, R. 2000. Introduction: The Dynamics of Social Change in R. Berthoud and J. Gershuny (eds), Seven Years in the Lives of British Families: Evidence on the Dynamics of Social Change from the British Household Panel Survey. Bristol: Policy Press.
Bowden, A. & Fox-Rushby, J. A. 2003. A systematic and critical review of the process of translation and adaptation of generic health-related quality of life measures in Africa, Asia, Eastern Europe, the Middle East, South America. *Social science & medicine,* 57**,** 1289-1306.
Bowling, A. 1999. Health-related quality of life: A discussion of the concept, its use and measurement background: The `quality of life' By A. Bowling at http://info.worldbank.org/etools/docs/library/48475/m2s5bowling.pdf. *Adapting to Change Core Course, September 1999, accessed 2/01/2018.*
Bowling, A. 2014. Quality of life: measures and meanings in social care research. *Methods Review.* NIHR School for social care.
Brehaut, J. C., Kohen, D. E., Raina, P., Walter, S. D., Russell, D. J., Swinton, M., O'donnell, M. & Rosenbaum, P. 2004. The health of primary caregivers of children with cerebral palsy: how does it compare with that of other Canadian caregivers? *Pediatrics,* 114**,** e182-e191.
Bright, T., Mulwafu, W., Thindwa, R., Zuurmond, M. & Polack, S. 2017. Reasons for low uptake of referrals to ear and hearing services for children in Malawi. *PloS one,* 12**,** e0188703.
Bronfenbrenner, U. 1992. Ecological systems theory. *In:* VASTA, R. (ed.) *Six theories of child development: Revised formulations and current issues* Jessica Kingsley Publishers.
Bronfenbrenner, U. 1994a. Ecological models of human development. *Readings on the development of children,* 2**,** 37-43.
Bronfenbrenner, U. 1994b. Ecological models of human development. *International Encyclopedia of Education, Volume 3, pp. 1643-1647.* Oxford: Elselvier,.
Brouwers, C., Van Brakel, W. & Cornielje, H. 2011. Quality of life, perceived stigma, activity and participation of people with leprosy-related disabilities in south-east Nepal. *Disability, CBR & Inclusive Development,* 22**,** 16-34.

Bunning, K., Gona, J. K., Newton, C. R., Andrews, F., Blazey, C., Ruddock, H., Henery, J. & Hartley, S. 2020. Empowering self-help groups for caregivers of children with disabilities in Kilifi, Kenya: Impacts and their underlying mechanisms. *Plos one,* 15**,** e0229851.

Bunning, K., Gona, J. K., Newton, C. R. & Hartley, S. 2014a. Caregiver Perceptions of Children who have Complex Communication Needs Following a Home-based Intervention Using Augmentative and Alternative Communication in Rural Kenya: An Intervention Note. *AAC: Augmentative & Alternative Communication,* 30**,** 344-356.

Bunning, K., Gona, J. K., Newton, C. R. & Hartley, S. 2017. The perception of disability by community groups: Stories of local understanding, beliefs and challenges in a rural part of Kenya. *PLoS One,* 12**,** e0182214.

Bunning, K., Gona, J. K., Odera-Mung'ala, V., Newton, C. R., Geere, J.-A., Hong, C. S. & Hartley, S. 2014b. Survey of rehabilitation support for children 0–15 years in a rural part of Kenya. *Disability and rehabilitation,* 36**,** 1033-1041.

Camfield, L., Choudhury, K. & Devine, J. 2009a. Well-being, happiness and why relationships matter: Evidence from Bangladesh. *Journal of Happiness Studies,* 10**,** 71-91.

Camfield, L., Crivello, G. & Woodhead, M. 2009b. Wellbeing research in developing countries: Reviewing the role of qualitative methods. *Social Indicators Research,* 90**,** 5-31.

Camfield, L. & Skevington, S. M. 2008. On subjective well-being and quality of life. *Journal of Health Psychology,* 13**,** 764-775.

Camfield, L. & Tafere, Y. 2009. 'No, living well does not mean being rich': Diverse understandings of well-being among 11–13-year-old children in three Ethiopian communities. *Journal of children and poverty,* 15**,** 119-138.

Cantril, H. 1965. *Pattern of human concerns,* New Brunswick, N.J., Rutgers University Press.

Carersuk. *What is a Carer?* [Online]. Available: https://www.carersuk.org/news-and-campaigns/news/not-being-able-to-talk-to-friends-about-caring-leaves-one-in-three-unpaid-carers-socially-isolated [Accessed 03/08 2020].

Centers for Disease Control. 2015. *The Social-Ecological Model: A Framework for Prevention at https://www.cdc.gov/violenceprevention/about/social-ecologicalmodel.html* [Online]. [Accessed 20/02 2018].

Centers for Disease Control and Prevention. *Caregiving at https://www.cdc.gov/aging/caregiving/index.htm* [Online]. [Accessed 03/08/2020 2020].

Centers for Disease Control and Prevention. *Facts about developmental disabilities* [Online]. Available: https://www.cdc.gov/ncbddd/developmentaldisabilities/facts.html [Accessed 04/05/2021.

Cerebral Palsy Association. 2008. *Hambisela: Towards Excellence in Cerebral Palsy. A Training resource for facilitators, parents, caregivers and persons with cerebral palsy* [Online]. Port Elizabeth: Cerebral Palsy Association. Available: www.hambisela.co.za. [Accessed February 2015].

Chambers, R. 1983. Rural Development-Putting the Last First: Longman Scientific and Technical. *Harlow, UK*.

Chambers, R. 1994a. Paradigm shifts and the practice of participatory research and development: Instiute of Development Studies Working paper at https://opendocs.ids.ac.uk/opendocs/bitstream/handle/20.500.12413/3712/WP2.pdf?seq. IDS.

Chambers, R. 1994b. Participatory rural appraisal (PRA): Challenges, potentials and paradigm. *World Development,* 22**,** 1437-1454.

Chambers, R. 2012. *Robert Chambers on the Fifth Power (the power to empower) available at https://oxfamblogs.org/fp2p/robert-chambers-on-the-fifth-power-the-power-to-empower/* [Online]. [Accessed 2nd February 2016].

Chiluba, B. C. & Moyo, G. 2017. Caring for a cerebral palsy child: a caregivers perspective at the University Teaching Hospital, Zambia. *BMC Research Notes,* 10**,** 724.

Chiu, M. Y. L., Yang, X., Wong, F. H. T., Li, J. H. & Li, J. 2013. Caregiving of children with intellectual disabilities in C hina – an examination of affiliate stigma and the cultural thesis. *Journal of Intellectual Disability Research,* 57**,** 1117-1129.
Coghlan, D. & Brydon-Miller, M. 2014. *The SAGE encyclopedia of action research*, Sage.
Collins, P. Y., Pringle, B., Alexander, C., Darmstadt, G. L., Heymann, J., Huebner, G., Kutlesic, V., Polk, C., Sherr, L. & Shih, A. 2017. Global services and support for children with developmental delays and disabilities: Bridging research and policy gaps. *PLoS medicine,* 14**,** e1002393.
Colver, A., Fairhurst, C. & Pharoah, P. O. D. 2013a. Cerebral Palsy Published online November 20, 2013 http://dx.doi.org/10.1016/S0140-6736(13)61835-8. *The Lancet*.
Colver, A., Fairhurst, C. & Pharoah, P. O. D. 2013b. Cerebral Palsy Published online November 20, 2013 http://dx.doi.org/10.1016/S0140-6736(13)61835-8. *The Lancet*.
Corrigan, P. W., Kerr, A. & Knudsen, L. 2005. The stigma of mental illness: Explanatory models and methods for change. *Applied and Preventive Psychology,* 11**,** 179-190.
Cox, E. 2015. Coaching and adult learning: Theory and practice. *New Directions for Adult and Continuing Education,* 2015**,** 27-38.
Craig, P., Dieppe, P., Macintyre, S., Michie, S., Nazareth, I. & Petticrew, M. 2008. Developing and evaluating complex interventions: the new Medical Research Council guidance. *Bmj,* 337**,** a1655.
Creswell, J. W. 2013. *Research design: Qualitative, quantitative, and mixed methods approaches,* London, SAGE.
Creswell, J. W. & Creswell, J. D. 2017. *Research design: Qualitative, quantitative, and mixed methods approaches*, Sage publications.
Crivello, G., Camfield, L. & Woodhead, M. 2009. How can children tell us about their wellbeing? Exploring the potential of participatory research approaches within young lives. *Social indicators research,* 90**,** 51-72.
Dadi, A. F., Miller, E. R. & Mwanri, L. 2020. Postnatal depression and its association with adverse infant health outcomes in low-and middle-income countries: a systematic review and meta-analysis. *BMC pregnancy and childbirth,* 20**,** 1-15.
Dambi, J. & Jelsma, J. 2014a. The impact of hospital-based and community based models of cerebral palsy rehabilitation: A quasi-experimental study. *BMC paediatrics,* 14.
Dambi, J. M. & Jelsma, J. 2014b. The impact of hospital-based and community based models of cerebral palsy rehabilitation: a quasi-experimental study. *BMC Pediatr,* 14.
Dambi, J. M., Mandizvidza, C., Chiwaridzo, M., Nhunzvi, C. & Tadyanemhandu, C. 2016. Does an educational workshop have an impact on caregivers' levels of knowledge about cerebral palsy? A comparative, descriptive cross-sectional survey of Zimbabwean caregivers. *Malawi Medical Journal,* 28**,** 167-173.
Darawsheh, W. & Stanley, M. 2014. Reflexivity in research: Promoting rigour, reliability and validity in qualitative research. *International Journal of Therapy and Rehabilitation,* 21**,** 560-568.
De Sas Kropiwnicki, Z. O., Elphick, J. & Elphick, R. 2014. Standing by themselves: Caregivers' strategies to ensure the right to education for children with disabilities in Orange Farm, South Africa. *Childhood,* 21**,** 354-368.
De Silva, M. J., Breuer, E., Lee, L., Asher, L., Chowdhary, N., Lund, C. & Patel, V. 2014. Theory of change: a theory-driven approach to enhance the Medical Research Council's framework for complex interventions. *Trials,* 15**,** 1-13.
Den Besten, J., Cornielje, M. T., Cornielje, H. & Botwey, D. N. 2016. Supporting Parents in Caring for Children with Disability in Ghana. *Disability, CBR & Inclusive Development,* 27**,** 87-101.
Deneulin, S. & Mcgregor, J. A. 2010. The capability approach and the politics of a social conception of wellbeing. *European Journal of Social Theory,* 13**,** 501-519.
Denham, A. R. 2017. *Spirit children: illness, poverty, and infanticide in northern Ghana*, University of Wisconsin Pres.

Denham, A. R., Adongo, P. B., Freydberg, N. & Hodgson, A. 2010. Chasing spirits: Clarifying the spirit child phenomenon and infanticide in Northern Ghana. *Social Science & Medicine,* 71**,** 608-615.

Dogbe, J. A., Kyeremateng, J. D. A., Opoku, M. P., Nketsia, W. & Hammond, C. 2019. 'There is family tension, but they understand…': familial and sibling relationships following the diagnosis of cerebral palsy in children in Ghana. *International Journal of Developmental Disabilities*.

Donald, K. A., Kakooza, A. M., Wammanda, R. D., Mallewa, M., Samia, P., Babakir, H., Bearden, D., Majnemer, A., Fehlings, D. & Shevell, M. 2015. Pediatric Cerebral Palsy in Africa Where Are We? *Journal of child neurology,* 30**,** 963-971.

Donald, K. A., Samia, P., Kakooza-Mwesige, A. & Bearden, D. 2014. Pediatric Cerebral Palsy in Africa: A Systematic Review. *Seminars in pediatric neurology,* 21**,** 30-35.

Eiser, C. & Morse, R. 2001. Can parents rate their child's health-related quality of life? Results of a systematic review. *Quality of Life Research,* 10**,** 347-357.

Elafros, M. A., Sakubita-Simasiku, C., Atadzhanov, M., Haworth, A., Chomba, E. & Birbeck, G. L. 2013. Stigma and psychiatric morbidity among mothers of children with epilepsy in Zambia. *International health,* 5**,** 288-294.

Elphick, J., De Saskropiwnicki, Z. & Elphick, R. 2016. "Our children have the right to an education too": Strategies Employed by Orange Farm Caregivers of Children with Disabilities in Pursuit of the Right to a Basic Education. *Disability, CBR & Inclusive Development,* 26**,** 101-116.

England, K. V. 1994. Getting personal: Reflexivity, positionality, and feminist research. *The professional geographer,* 46**,** 80-89.

Eriksson, M., Ghazinour, M. & Hammarström, A. 2018. Different uses of Bronfenbrenner's ecological theory in public mental health research: what is their value for guiding public mental health policy and practice? *Social Theory & Health,* 16**,** 414-433.

Fayers, P. M. & Machin, D. 2013. *Quality of life: the assessment, analysis and interpretation of patient-reported outcomes*, John Wiley & Sons.

Fiest, K. M., Birbeck, G. L., Jacoby, A. & Jette, N. 2014. Stigma in epilepsy. *Current neurology and neuroscience reports,* 14**,** 444.

Freire, P. 1996. Pedagogy of the oppressed (revised). *New York: Continuum*.

Froehlich-Grobe, K., Nary, D. E., Van Sciver, A., Lee, J. & Little, T. D. 2011. Measuring height without a stadiometer: empirical investigation of four height estimates among wheelchair users. *American journal of physical medicine & rehabilitation/Association of Academic Physiatrists,* 90**,** 658.

Gaventa, J. 2005. Reflections of the Uses of the "Power Cube‟ Approach for Analyzing the Spaces, Places and Dynamics of Civil Society Participation and Engagement‟ available at https://www.participatorymethods.org/resource/reflections-uses-power-cube-approach-analysing-spaces-places-and-dynamics-civil-society. *CFP Evaluation Series No 4.* Institute of develpment studies.

Geere, J., Gona, J., Omondi, F., Kifalu, M., Newton, C. & Hartley, S. 2013. Caring for children with physical disability in Kenya: potential links between caregiving and carers' physical health. *Child: care, health and development,* 39**,** 381-392.

George, C. E., Norman, G., Benjamin, T. E. & Mukherjee, D. 2014. Barriers to Early Diagnosis, Intervention and Social Integration of Children with Developmental Disabilities: A Qualitative Study from Rural Villages and a Poor Urban Settlement of Bangalore, South India. *Disability, CBR & Inclusive Development,* 25**,** 23.

Ghana Statistical Service March 2015. Ghana Demographic and Health Survey 2014. Accra: Ghana Statistical Service.

Gill, T. M. 1995. Quality of life assessment: values and pitfalls. *Journal of the Royal Society of Medicine,* 88**,** 680.

Gladstone, M. 2010. A review of the incidence and prevalence, types and aetiology of childhood cerebral palsy in resource-poor settings. *Annals of Tropical Paediatrics,* 30**,** 181-196.

Gladstone, M., Mclinden, M., Douglas, G., Jolley, E., Schmidt, E., Chimoyo, J., Magombo, H. & Lynch, P. 2017. 'Maybe I will give some help…. maybe not to help the eyes but different help': an analysis of care and support of children with visual impairment in community settings in Malawi. *Child: Care, Health and Development,* 43**,** 608-620.

Goffman, E. 1963. *Stigma: Notes on the management of spoiled identity,* New York, Simon and Schuster.

Gona, J., Newton, C., Hartley, S. & Bunning, K. 2014. A home-based intervention using augmentative and alternative communication (AAC) techniques in rural Kenya: what are the caregivers' experiences? *Child: care, health and development,* 40**,** 29-41.

Gona, J. K., Mung'ala-Odera, V., Newton, C. R. & Hartley, S. 2011. Caring for children with disabilities in Kilifi, Kenya: what is the carer's experience? *Child Care Health Dev,* 37**,** 175-83.

Gona, J. K., Newton, C., Hartley, S. & Bunning, K. 2020. Development of self-help groups for caregivers of children with disabilities in Kilifi, Kenya: Process evaluation. *African Journal of Disability (Online),* 9**,** 1-9.

Gona, J. K., Newton, C. R., Hartley, S. & Bunning, K. 2018. Persons with disabilities as experts-by experience: using personal narratives to affect community attitudes in Kilifi, Kenya. *BMC international health and human rights,* 18**,** 1-12.

Grant, M. J. & Booth, A. 2009. A typology of reviews: an analysis of 14 review types and associated methodologies. *Health information & libraries journal,* 26**,** 91-108.

Green, J. & Thorogood, N. 2009. *Qualitative methods for health research,* London, SAGE.

Groce, N., Kett, M., Lang, R. & Trani, J.-F. 2011. Disability and poverty: The need for a more nuanced understanding of implications for development policy and practice. *Third World Quarterly,* 32**,** 1493-1513.

Groce, N. E., Kerac, M., Farkas, A., Schultink, W. & Bieler, R. B. 2013. Inclusive nutrition for children and adults with disabilities. *The Lancet Global Health*.

Gulliford, M., Figueroa-Munoz, J., Morgan, M., Hughes, D., Gibson, B., Beech, R. & Hudson, M. 2002. What does' access to health care'mean? *Journal of health services research & policy,* 7**,** 186-188.

Gupta, V. B., Mehrotra, P. & Mehrotra, N. 2012. Parental stress in raising a child with disabilities in India. *Disability, CBR & Inclusive Development,* 23**,** 41-52.

Haegele, J. A. & Hodge, S. 2016. Disability discourse: Overview and critiques of the medical and social models. *Quest,* 68**,** 193-206.

Hanass-Hancock, J., Nene, S., Deghaye, N. & Pillay, S. 2017. 'These are not luxuries, it is essential for access to life': Disability related out-of-pocket costs as a driver of economic vulnerability in South Africa. *African Journal of Disability (Online),* 6**,** 1-10.

Harrison, A., Short, S. E. & Tuoane-Nkhasi, M. 2014. Re-focusing the gender lens: Caregiving women, family roles and HIV/AIDS vulnerability in Lesotho. *AIDS and Behavior,* 18**,** 595-604.

Hartley, S., Ojwang, V. P., Bagawemu, A., Ddamulira, M. & Chavuta, A. 2005. How do carers of disabled children cope? The Uganda perspective. Child: Care, Health and Development. 31 2 167-180.

Hashemi, G., Wickenden, M., Bright, T. & Kuper, H. 2020. Barriers to accessing primary healthcare services for people with disabilities in low and middle-income countries, a Meta-synthesis of qualitative studies. *Disability and Rehabilitation***,** 1-14.

Helliwell Jf, Layard R & J, S. 2013. World Happiness Report. New York: Sustainable Development Solutions Network.

Helliwell, J. F. & Barrington-Leigh, C. P. 2010. Measuring and understanding subjective well-being. *Canadian Journal of Economics/Revue canadienne d'économique,* 43**,** 729-753.

Heng-Hao, C. 2009. From housewives to activists: Lived experiences of mothers for disability rights in Taiwan. *Asian Journal of Women's studies,* 15**,** 34-59.

Hepperlen, R. A., Rabaey, P., Ament-Lemke, A. & Manley, H. 2021. Caring for a child with a disability in a Zambian community: A study using photo-elicitation. *Child: Care, Health and Development*.

Herba, C. M., Glover, V., Ramchandani, P. G. & Rondon, M. B. 2016. Maternal depression and mental health in early childhood: an examination of underlying mechanisms in low-income and middle-income countries. *The Lancet Psychiatry,* 3**,** 983-992.

Huang, Y. P., Kellett, U. & St John, W. 2012. Being concerned: caregiving for Taiwanese mothers of a child with cerebral palsy. *Journal of clinical nursing,* 21**,** 189-197.

Hughes, B. & Paterson, K. 1997. The social model of disability and the disappearing body: Towards a sociology of impairment. *Disability & society,* 12**,** 325-340.

Ingstad, B. 1990. The disabled person in the community: social and cultural aspects. *International journal of rehabilitation research. recherches de readaptation,* 13**,** 187-194.

Jones, L., Bellis, M. A., Wood, S., Hughes, K., Mccoy, E., Eckley, L., Bates, G., Mikton, C., Shakespeare, T. & Officer, A. 2012. Prevalence and risk of violence against children with disabilities: a systematic review and meta-analysis of observational studies. *The Lancet,* 380**,** 899-907.

Jones, S. J. 1997. VI. Reflexivity and feminist practice: Ethical dilemmas in negotiating meaning. *Feminism & Psychology,* 7**,** 348-353.

Kassah, A. K., Kassah, B. L. L. & Agbota, T. K. 2012. Abuse of disabled children in Ghana. *Disability & Society,* 27**,** 689-701.

Kelly, A., Ghalaieny, T. & Devitt, C. 2012a. A Pilot Study of Early Intervention for Families With Children With or at Risk of an Intellectual Disability in Northern Malawi. *Journal of Policy & Practice in Intellectual Disabilities,* 9**,** 195-205.

Kelly, A., Ghalaieny, T. & Devitt, C. 2012b. A pilot study of early intervention for families with children with or at risk of an intellectual disability in Northern Malawi. *Journal of Policy and Practice in Intellectual Disabilities,* 9**,** 195-205.

Kerac, M., Postels, D. G., Mallewa, M., Jalloh, A. A., Voskuijl, W. P., Groce, N., Gladstone, M. & Molyneux, E. The interaction of malnutrition and neurologic disability in Africa. Seminars in pediatric neurology, 2014. Elsevier, 42-49.

Khan, N. Z., Ferdous, S., Munir, S., Huq, S. & Mcconachie, H. 1998. Mortality of urban and rural young children with cerebral palsy in Bangladesh. *Developmental Medicine & Child Neurology,* 40**,** 749-753.

Kidman, R. & Heymann, J. 2016. Caregiver supportive policies to improve child outcomes in the wake of the HIV/AIDS epidemic: An analysis of the gap between what is needed and what is available in 25 high prevalence countries. *AIDS care,* 28**,** 142-152.

Kielman, K., Ctaldo, F. & Seeley, J. 2012. Introduction to qualitative research methodology Research Methodology: A training manual avialable at http://www.evidence4action.org/index.php?option=com_content&view=article&id=152:introduction-to-qualitative-research-methodology-training-manual&catid=1:latest&Itemid=100050.

Kippax, S., Stephenson, N., Parker, R. G. & Aggleton, P. 2013. Between individual agency and structure in HIV prevention: understanding the middle ground of social practice. *American journal of public health,* 103**,** 1367-1375.

Knowles, M. 1984. *The Adult Learning Theory - Andragogy* [Online]. Available: https://elearningindustry.com/the-adult-learning-theory-andragogy-of-malcolm-knowles [Accessed 17/02/2015.

Knowles, M. S., Holton, E. & Swanson, R. 2005. The adult learner: the definitive classic in adult education and human resource development (6th). *Burlington, MA: Elsevier*.

Kohli-Lynch, M., Tann, C. J. & Ellis, M. E. 2019. Early Intervention for Children at High Risk of Developmental Disability in Low-and Middle-Income Countries: A Narrative Review. *International journal of environmental research and public health,* 16**,** 4449.

Kuper, H., Monteath-Van Dok, A., Wing, K., Danquah, L., Evans, J., Zuurmond, M. & Gallinetti, J. 2014. The Impact of Disability on the Lives of Children; Cross-Sectional Data Including 8,900 Children with Disabilities and 898,834 Children without Disabilities across 30 Countries. *PloS one,* 9**,** e107300.

Kyerematen**g**, J. D. A., Edusei, A., Dogbe, J. A., Opoku, M. P., Nketsia, W., Hammond, C. & Afriyie, S. A. 2019. Experiences of primary caregivers of children with cerebral palsy across the trajectory of diagnoses in Ghana. *African Journal of Disability,* 8**,** 577.

Lamptey, D. 2019. Health beliefs and behaviours of families towards the health needs of children with intellectual and developmental disabilities (IDD) in Accra, Ghana. *Journal of Intellectual Disability Research,* 63**,** 12-20.

Lang, R. & Stone, E. 1999. Empowerment and CBR? Issues raised by the South Indian experience. *Disability and development: Learning from action and research on disability in the majority world***,** 130-148.

Levesque, J.-F., Harris, M. F. & Russell, G. 2013. Patient-centred access to health care: conceptualising access at the interface of health systems and populations. *International journal for equity in health,* 12**,** 1-9.

Link, B. G. & Phelan, J. 2014. Stigma power. *Social Science & Medicine,* 103**,** 24-32.

Link, B. G. & Phelan, J. C. 2001. Conceptualizing stigma. *Annual review of Sociology,* 27**,** 363-385.

Link, B. G. & Phelan, J. C. 2006. Stigma and its public health implications. *The Lancet,* 367**,** 528-529.

Livingston, J. D. & Boyd, J. E. 2010. Correlates and consequences of internalized stigma for people living with mental illness: A systematic review and meta-analysis. *Social science & medicine,* 71**,** 2150-2161.

Lshtm & Hambisela. 2013. *Getting to know Cerebral Palsy: working with parent groups- a training resource for facilitators, parents, caregivers and persons with cerebral palsy* [Online]. London. Available: https://www.ubuntu-hub.org/resources/gtkcp/ [Accessed 23/09/2016 2016].

Luttrell, C., Quiroz, S., Scrutton, C. & Bird, K. 2009a. *Understanding and operationalising empowerment,* London, Overseas Development Institute.

Luttrell, C., Quiroz, S., Scrutton, C. & Bird, K. 2009b. Understanding and operationalising empowerment: working paper 308. London: ODI.

Lynch, P., Gladstone, M., Mclinden, M., Douglas, G., Jolley, E., Schmidt, E. & Chimoyo, J. 2018. 'I have learnt to love the child and give opportunities to play with peers': A feasibility study of the training programme to support parents of young children with visual impairment in Malawi. *Journal of Early Childhood Research,* 16**,** 210-225.

Machuki, F. N., Munyoki, G. & Kabue, P. 2016. Care of children with cerebral palsy among guardians attending occupational therapy clinic at kenyatta national hospital, nairobi city county, kenya. *East African Medical Journal,* 93**,** 606-619.

Mactaggart, I., Banks, L. M., Kuper, H., Murthy, G., Sagar, J., Oye, J. & Polack, S. 2018. Livelihood opportunities amongst adults with and without disabilities in Cameroon and India: A case control study. *PloS one,* 13**,** e0194105.

Mak, W. W. & Cheung, R. Y. 2008. Affiliate stigma among caregivers of people with intellectual disability or mental illness. *Journal of Applied Research in Intellectual Disabilities,* 21**,** 532-545.

Masulani-Mwale, C., Kauye, F., Gladstone, M. & Mathanga, D. 2019. Development of a psycho-social intervention for reducing psychological distress among parents of children with intellectual disabilities in Malawi. *PLoS ONE,* 14.

Masulani-Mwale, C., Mathanga, D., Silungwe, D., Kauye, F. & Gladstone, M. 2016. Parenting children with intellectual disabilities in Malawi: the impact that reaches beyond coping? *Child: Care, Health & Development,* 42**,** 871-880.

Matt, S. B. 2014. Perceptions of disability among parents of children with disabilities in Nicaragua: Implications for future opportunities and health care access. *Disability Studies Quarterly,* 34.

Mbazzi, F. B., Nalugya, R., Kawesa, E., Nambejja, H., Nizeyimana, P., Ojok, P., Van Hove, G. & Seeley, J. 2020. 'Obuntu Bulamu'–Development and Testing of an Indigenous Intervention for Disability Inclusion in Uganda. *Scandinavian Journal of Disability Research,* 22**,** 403-417.
Mcconachie, H., Huq, S., Munir, S., Ferdous, S., Zaman, S. & Khan, N. Z. 2000. A randomized controlled trial of alternative modes of service provision to young children with cerebral palsy in Bangladesh. *The Journal of Pediatrics,* 137**,** 769-776.
Mcconkey, R., Kahonde, C. & Mckenzie, J. 2016. Tackling Stigma in Developing Countries: The Key Role of Families. *Intellectual Disability & Stigma: Stepping out from the Margins.* London: Palgrave-Macmillan.
Mcconkey, R., Mariga, L., Braadland, N. & Mphole, P. 2000. Parents as trainers about disability in low income countries. *International Journal of Disability, Development and Education,* 47**,** 309-317.
Mcdougall, J., Bedell, G. & Wright, V. 2013. The youth report version of the Child and Adolescent Scale of Participation (CASP): Assessment of psychometric properties and comparison with parent report. *Child: care, health and development,* 39**,** 512-522.
Mckenzie, J. & Mcconkey, R. 2016. Caring for adults with intellectual disability: The perspectives of family carers in South Africa. *Journal of Applied Research in Intellectual Disabilities,* 29**,** 531-541.
Mcleod, S. 2007. Maslow's hierarchy of needs. *Simply psychology,* 1.
Mcleroy, K. R., Bibeau, D., Steckler, A. & Glanz, K. 1988. An ecological perspective on health promotion programs. *Health education quarterly,* 15**,** 351-377.
Mitra, S., Posarac, A. & Vick, B. 2011. *Disability and poverty in developing countries: A snapshot from the World Health Survey*, World Bank.
Mitra, S., Posarac, A. & Vick, B. 2013. Disability and poverty in developing countries: a multidimensional study. *World Development,* 41**,** 1-18.
Mitra, S. & Shakespeare, T. 2019. Remodeling the ICF. *Disability and health journal,* 12**,** 337-339.
Mkabile, S., Garrun, K. L., Shelton, M. & Swartz, L. 2021. African families' and caregivers' experiences of raising a child with intellectual disability: A narrative synthesis of qualitative studies. *African Journal of Disability,* 10.
Mkabile, S. & Swartz, L. 2020. Caregivers' and parents' explanatory models of intellectual disability in Khayelitsha, Cape Town, South Africa. *Journal of Applied Research in Intellectual Disabilities,* 33**,** 1026-1037.
Mlinda, S. J., Leyna, G. H. & Massawe, A. 2018. The effect of a practical nutrition education programme on feeding skills of caregivers of children with cerebral palsy at Muhimbili National Hospital, in Tanzania. *Child: Care, Health & Development,* 44**,** 452-461.
Mobarak, R., Khan, N. Z., Munir, S., Zaman, S. S. & Mcconachie, H. 2000. Predictors of stress in mothers of children with cerebral palsy in Bangladesh. *J Pediatr Psychol,* 25**,** 427-33.
Mofokeng, M. & Van Der Wath, A. E. 2017. Challenges experienced by parents living with a child with attention deficit hyperactivity disorder. *Journal of Child & Adolescent Mental Health,* 29**,** 137-145.
Moodley, J. & Graham, L. 2015. The importance of intersectionality in disability and gender studies. *Agenda,* 29**,** 24-33.
Morris, J. 1991. Feminist Research and community care *Pride against prejudice: Transforming attitudes to disability.* London: The Women's Press.
Morrison, J., Thapa, R., Hartley, S., Osrin, D., Manandhar, M., Tumbahangphe, K., Neupane, R., Budhathoki, B., Sen, A. & Pace, N. 2010. Understanding how women's groups improve maternal and newborn health in Makwanpur, Nepal: a qualitative study. *International health,* 2**,** 25-35.
Moser, C. 1989. Community participation in urban projects in the Third World. *Progress in planning,* 32**,** 71-133.

Muderedzi, J., Eide, A. H., Braathen, S. H. & Stray-Pedersen, B. 2017. Perceptions and treatment of children with cerebral palsy among the Tonga of Binga in Zimbabwe. *Cogent Social Sciences,* 3.

Murthy, G. V., Mactaggart, I., Mohammad, M., Islam, J., Noe, C., Khan, A. I., Foster, A., Smith, A., Qureshi, B. & Gilbert, C. 2014. Assessing the prevalence of sensory and motor impairments in childhood in Bangladesh using key informants. *Archives of disease in childhood***,** archdischild-2014-305937.

Muthukrishna, N. & Ebrahim, H. 2014. Motherhood and the disabled child in contexts of early education and care. *Childhood,* 21**,** 369-384.

Nakamanya, S., Siu, G. E., Lassman, R., Seeley, J. & Tann, C. J. 2015. Maternal experiences of caring for an infant with neurological impairment after neonatal encephalopathy in Uganda: a qualitative study. *Disability & Rehabilitation,* 37**,** 1470-1476.

Namazzi, G., Hanson, C., Nalwadda, C., Tetui, M., Nampijja, M., Waiswa, P., Tumwine, J. K. & Hildenwall, H. 2020. Caring for children with neurodevelopmental disability: Experiences from caretakers and health workers in rural eastern Uganda. *PloS one,* 15**,** e0236488.

Nampijja, M., Webb, E., Nanyunja, C., Sadoo, S., Nalugya, R., Nyonyintono, J., Muhumuza, A., Ssekidde, M., Katumba, K. & Magnusson, B. 2019. Randomised controlled pilot feasibility trial of an early intervention programme for young infants with neurodevelopmental impairment in Uganda: a study protocol. *BMJ open,* 9**,** e032705.

Neale, B. & Flowerdew, J. 2003. Time, texture and childhood: The contours of longitudinal qualitative research. *International Journal of Social Research Methodology,* 6**,** 189-199.

Nesbitt, R., Mackey, S., Kuper, H., Muhit, M. & Murthy, G. 2012. Predictors of referral uptake in children with disabilities in Bangladesh-Exploring barriers as a first step to improving referral provision. *Disability and Rehabilitation,* 34**,** 1089-1095.

Ngubane-Mokiwa, S. A. 2018. Ubuntu considered in light of exclusion of people with disabilities. *African Journal of Disability (Online),* 7**,** 1-7.

Ngubane, M. & Chetty, V. 2017. Caregiver satisfaction with a multidisciplinary community-based rehabilitation programme for children with cerebral palsy in South Africa. *South African Family Practice,* 59**,** 35-40.

Nyante, G. G. 2016. *An exploration of the experiences and perceptions of primary caregivers of children with cerebral palsy living in rural communities in Ghana at at https://curve.coventry.ac.uk/open/file/8315e76f-aa7a-4532-9cec-c51033cc12a1/1/Gifty%20Gyamah%20Nyante%20PhD%20Thesis%20.pdf.* PhD, Coventry University

Nyante, G. G. & Carpenter, C. 2019. The experience of carers of children with cerebral palsy living in rural areas of Ghana who have received no rehabilitation services: A qualitative study. *Child: Care, Health & Development,* 45**,** 815-822.

Nyante, G. G., Carpenter, C. & Igo, S. 2017. Conceptualization of cerebral palsy: Experiences of caregivers of children with cerebral palsy in Ghanaian rural communities. *Numid Horizon International Journal of Nursing and Midwifery,* 1**,** 19-28.

Olusanya, B. O., Davis, A. C., Wertlieb, D., Boo, N.-Y., Nair, M., Halpern, R., Kuper, H., Breinbauer, C., De Vries, P. J. & Gladstone, M. 2018. Developmental disabilities among children younger than 5 years in 195 countries and territories, 1990–2016: a systematic analysis for the Global Burden of Disease Study 2016. *The Lancet Global Health,* 6**,** e1100-e1121.

Oti-Boadi, M. 2017. Exploring the Lived Experiences of Mothers of Children With Intellectual Disability in Ghana. *SAGE Open,* 7.

Paget, A., Mallewa, M., Chinguo, D., Mahebere-Chirambo, C. & Gladstone, M. 2015. "It means you are grounded" - caregivers' perspectives on the rehabilitation of children with neurodisability in Malawi. *Disabil Rehabil***,** 1-12.

Palmer, M. & Harley, D. 2012. Models and measurement in disability: an international review. *Health Policy and Planning,* 27**,** 357-364.

Parker, R. & Aggleton, P. 2003. HIV/AIDS-related stigma and discrimination: a conceptual framework and implications for action. *Social Science and Medicine*, 13-24.
Patel, P., Baier, J., Baranov, E., Khurana, E., Gambrah-Sampaney, C., Johnson, A., Monokwane, B. & Bearden, D. 2017. Health beliefs regarding pediatric cerebral palsy among caregivers in Botswana: A qualitative study. *Child: care, health and development,* 43**,** 861-868.
Peters, D. H., Garg, A., Bloom, G., Walker, D. G., Brieger, W. R. & Hafizur Rahman, M. 2008. Poverty and access to health care in developing countries. *Annals of the new York Academy of Sciences,* 1136**,** 161-171.
Peters, M. D., Godfrey, C. M., Khalil, H., Mcinerney, P., Parker, D. & Soares, C. B. 2015. Guidance for conducting systematic scoping reviews. *JBI Evidence Implementation,* 13**,** 141-146.
Pfeiffer, D. 2000. The devils are in the details: The ICIDH2 and the disability movement. *Disability & Society,* 15**,** 1079-1082.
Pousada, M., Guillamón, N., Hernández-Encuentra, E., Muñoz, E., Redolar, D., Boixadós, M. & Gómez-Zúñiga, B. 2013. Impact of caring for a child with cerebral palsy on the quality of life of parents: a systematic review of the literature. J. Dev. Phys. Disabil. [Internet]. 2013 [cited 2014 Jul 12];25:545–77. Available from: http://link.springer.com/10.1007/s10882-013-9332-6.
Pretorius, C. & Steadman, J. 2018. Barriers and Facilitators to Caring for a Child with Cerebral Palsy in Rural Communities of the Western Cape, South Africa. *Child Care in Practice,* 24**,** 413-430.
Raina, P., O'donnell, M., Rosenbaum, P., Brehaut, J., Walter, S. D., Russell, D., Swinton, M., Zhu, B. & Wood, E. 2005. The health and well-being of caregivers of children with cerebral palsy. *Pediatrics,* 115**,** e626-e636.
Retief, M. & Letšosa, R. 2018. Models of disability: A brief overview. *HTS Teologiese Studies/Theological Studies,* 74.
Rosato-Scott, C., Giles-Hansen, C., House, S., Wilbur, J., Macaulay, M., Barrington, D., Culmer, P., Bhakta, A. & Burke, L. 2019. Guidance on supporting people with incontinence in humanitarian and low-and middle-income contexts (LMICs) at https://doi.org/10.5518/100/13.
Rosenbaum, P. 2011. Family and quality of life: key elements in intervention in children with cerebral palsy. *Developmental Medicine & Child Neurology,* 53**,** 68-70.
Rosenbaum, P. & Gorter, J. 2012. The 'F-words' in childhood disability: I swear this is how we should think! *Child: care, health and development,* 38**,** 457-463.
Rosenbaum, P. & Stewart, D. 2004. The world health organization international classification of functioning, disability, and health: a model to guide clinical thinking, practice and research in the field of cerebral palsy. *Seminars in Pediatric Neurology,* 11**,** 5-10.
Rowlands, J. 1997. *Questionning emwpowerment: working with women in Honduras,* Oxford, Oxfam.
Ruta, D., Camfield, L. & Donaldson, C. 2007. Sen and the art of quality of life maintenance: Towards a general theory of quality of life and its causation. *The Journal of Socio-Economics,* 36**,** 397-423.
Ryan, S. & Runswick-Cole, K. 2008. Repositioning mothers: Mothers, disabled children and disability studies. *Disability & Society,* 23**,** 199-210.
Sandy, P., Kgole, J. & Mavundla, T. 2013a. Support needs of caregivers: Case studies in South Africa. *International Nursing Review,* 60**,** 344-350.
Sandy, P. T., Kgole, J. C. & Mavundla, T. R. 2013b. Support needs of caregivers: case studies in South Africa. *Int Nurs Rev,* 60**,** 344-50.
Scambler, G. 2009. Health-related stigma. *Sociology of health & illness,* 31**,** 441-455.
Scarpelli, A. C., Paiva, S. M., Pordeus, I. A., Varni, J. W., Viegas, C. M. & Allison, P. J. 2008. The Pediatric Quality of Life Inventory™(PedsQL™) family impact module: reliability and validity of the Brazilian version. *Health and Quality of Life Outcomes,* 6**,** 35.
Schatz, E. & Seeley, J. 2015. Gender, ageing and carework in East and Southern Africa: A review. *Global Public Health,* 10**,** 1185-1200.

Scior, K. 2016. Towards Understanding Intellectual Disability Stigma: Introduction. . *Intellectual Disability and Stigma: Stepping Out from the Margins. .* London: Palgrave Macmillan.
Scior, K., Addai-Davis, J., Kenyon, M. & Sheridan, J. 2013. Stigma, public awareness about intellectual disability and attitudes to inclusion among different ethnic groups. *Journal of Intellectual Disability Research,* 57**,** 1014-1026.
Sen, A. 1993. Capability and well-being. *In:* NUSSBAUM, M. & SEN, A. (eds.) *The quality of life* Oxford: Clarendon Press.
Sen, R. & Goldbart, J. 2005. Partnership in Action: Introducing family-based intervention for children with disability in urban slums of Kolkata, India. *International Journal of Disability, Development and Education,* 52**,** 275-311.
Sevenhuijsen, S. 2003. The place of care: The relevance of the feminist ethic of care for social policy. *Feminist theory,* 4**,** 179-197.
Shakespeare, T. 2012. Still a health issue. *Disability and health journal,* 5**,** 129-131.
Shakespeare, T. 2013. *Disability rights and wrongs revisited,* Oxon and New York, Routledge.
Shakespeare, T. & Watson, N. 2001. The social model of disability: an outdated ideology? *In:* BARNATT, S. N. & ALTMAN, B. M. (eds.) *Exploring theories and expanding methodologies: Where we are and where we need to go (Social Science and Disability).* Emerald Group Publishing Limited.
Shewchuk, R. & Elliott, T. R. 2000. Family caregiving in chronic disease and disability. *In:* FRANK, R. G. & ELLIOTT, T. R. (eds.) *Handbook of rehabilitation psychology* American Psychological Association.
Shin, J., Nhan, N., Lee, S. B., Crittenden, K., Flory, M. & Hong, H. 2009. The effects of a home-based intervention for young children with intellectual disabilities in Vietnam. *Journal of Intellectual Disability Research,* 53**,** 339-352.
Singogo, C., Mweshi, M. & Rhoda, A. 2015. Challenges experienced by mothers caring for children with cerebral palsy in Zambia. *South African Journal of Physiotherapy,* 71**,** 1-6.
Smythe, T., Adelson, J. & Polack, S. 2020a. Systematic review of interventions for reducing stigma experienced by children with disabilities and their families in low and middle-income countries: state of the evidence. *Tropical Medicine & International Health*.
Smythe, T., Zuurmond, M., Tann, C. J., Gladstone, M. & Kuper, H. 2020b. Early intervention for children with developmental disabilities in low and middle-income countries–the case for action. *International Health*.
Southwick, S. M., Bonanno, G. A., Masten, A. S., Panter-Brick, C. & Yehuda, R. 2014. Resilience definitions, theory, and challenges: Interdisciplinary perspectives. *European journal of psychotraumatology,* 5**,** 25338.
Stangl, A. L., Earnshaw, V. A., Logie, C. H., Van Brakel, W., Simbayi, L. C., Barré, I. & Dovidio, J. F. 2019. The Health Stigma and Discrimination Framework: a global, crosscutting framework to inform research, intervention development, and policy on health-related stigmas. *BMC medicine,* 17**,** 31.
Stata, S. 2013. Release 13. Statistical software. *StataCorp LP, College Station, TX*.
Stienstra, D. & Lee, T. M. L. 2019. Disabilities and Livelihoods: Rethinking a Conceptual Framework. *Societies,* 9**,** 67.
Storbeck, C. & Pittman, P. 2008. Early intervention in South Africa: moving beyond hearing screening. *International Journal of Audiology,* 47**,** S36-43.
Sultana, F. 2007. Reflexivity, positionality and participatory ethics: Negotiating fieldwork dilemmas in international research. *ACME: An international E-journal for Critical Geographies,* 6**,** 374-385.
Tekola, B., Kinfe, M., Girma, F., Hanlon, C. & Hoekstra, R. A. 2020. Perceptions and experiences of stigma among parents of children with developmental disorders in Ethiopia: A qualitative study. *Social Science & Medicine,* 256**,** N.PAG-N.PAG.

Tigere, B. & Makhubele, J. C. 2019. The experiences of parents of children living with disabilities at Lehlaba Protective Workshop in Sekhukhune district of Limpopo province. *African Journal of Disability,* 8**,** 528.
Tilahun, D., Hanlon, C., Fekadu, A., Tekola, B., Baheretibeb, Y. & Hoekstra, R. A. 2016. Stigma, explanatory models and unmet needs of caregivers of children with developmental disorders in a low-income African country: a cross-sectional facility-based survey. *BMC health services research,* 16**,** 152.
Tinney, M., Chiodo, A., Haig, A. & Wiredu, E. 2007. Medical rehabilitation in Ghana. *Disability and Rehabilitation,* 29**,** 921-927.
Tøssebro, J. 2004. Introduction to the special issue: Understanding disability.
Tripathy, P., Nair, N., Barnett, S., Mahapatra, R., Borghi, J., Rath, S., Gope, R., Mahto, D. & Sinha, R. 2010. Effect of a participatory intervention with women's groups on birth outcomes and maternal depression in Jharkhand and Orissa, India: a cluster-randomised controlled trial. *The Lancet,* 375**,** 1182-1192.
Un Women December 2018. The empowerment of women and girls with disabilities available at https://www.unwomen.org/en/digital-library/publications/2018/12/the-empowerment-of-women-and-girls-with-disabilities. New York.
Unicef 2013. State of the World's Children: children with disabilities New York: UNICEF.
Unicef. 2015. *Understanding the Social Ecological Model (SEM) and Communication for Development_Module 1:* [Online]. Available: https://webcache.googleusercontent.com/search?q=cache:9Rp1BgpBAeoJ:https://www.unicef.org/cbsc/files/Module_1_-_MNCHN_C4D_Guide.docx+&cd=9&hl=en&ct=clnk&gl=lk [Accessed 07/12/2017 2017].
United Nations. 1982. *Model Life Tables for Developing Countries at* [Online]. Available: http://www.un.org/esa/population/publications/Model_Life_Tables/Model_Life_Tables.htm [Accessed 20/09 2016].
United Nations. 1989. *The UN Convention on the rights of the Child* [Online]. Available: http://www.unicef.org.uk/UNICEFs-Work/Our-mission/UN-Convention/ [Accessed 04/09 2013].
United Nations. 2006. *UN Convention on the Rights of Persons with Disabilities* [Online]. Available: https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html [Accessed 04/09 2017].
United Nations 2012. Disability, Livelihood and poverty in Asia and the Pacific at https://www.unescap.org/sites/default/files/SDD_PUB_Disability-Livelihood.pdf.
United Nations. 2015. *Sustainable Development Goals* [Online]. Available: https://sustainabledevelopment.un.org/ [Accessed 26/09 2017].
Van Aswegen, T., Myezwa, H., Potterton, J. & Stewart, A. 2019. The effect of the Hambisela programme on stress levels and quality of life of primary caregivers of children with cerebral palsy: A pilot study. *South African Journal of Physiotherapy,* 75**,** 1-8.
Van Der Mark, E. J., Conradie, I., Dedding, C. W. & Broerse, J. E. 2019a. 'We create our own small world': daily realities of mothers of disabled children in a South African urban settlement. *Disability & Society,* 34**,** 95-120.
Van Der Mark, E. J., Conradie, I., Dedding, C. W. M. & Broerse, J. E. W. 2019b. Exploring adaptation and agency of mothers caring for disabled children in an urban settlement in South Africa: A qualitative study. *Women's Studies International Forum,* 76.
Van Der Mark, E. J. & Verrest, H. 2014. Fighting the odds: Strategies of female caregivers of disabled children in Zimbabwe. *Disability & Society,* 29**,** 1412-1427.
Varni, J. W., Sherman, S. A., Burwinkle, T. M., Dickinson, P. E. & Dixon, P. 2004. The PedsQL™ family impact module: preliminary reliability and validity. *Health and quality of life outcomes,* 2**,** 55.
Wallerstein, N. & Bernstein, E. 1988. Empowerment education: Freire's ideas adapted to health education. *Health education quarterly,* 15**,** 379-394.

Weiss, M. G. & Ramakrishna, J. 2006. Stigma interventions and research for international health. *The Lancet,* 367**,** 536-538.
Weiss, M. G., Ramakrishna, J. & Somma, D. 2006. Health-related stigma: rethinking concepts and interventions, P280. *Psychology, health & medicine,* 11**,** p.280.
Who & Unesco 2010. Community-based rehabilitation: CBR Guidelines, Empowerment Component at https://www.who.int/disabilities/cbr/guidelines/en/. *Geneva: WHO*.
Whoqol Group 1995. The World Health Organization quality of life assessment (WHOQOL): position paper from the World Health Organization. *Social Science & Medicine,* 41**,** 1403-1409.
Wong, V. C. 2011. Global developmental delay-a delay in development of terminology. *Developmental medicine and child neurology,* 53**,** 585.
Wood, E. & Rosenbaum, P. 2000. The gross motor function classification system for cerebral palsy: a study of reliability and stability over time. *Developmental Medicine & Child Neurology,* 42**,** 292-296.
World Confederation of Physical Therapy. *Ghana Physiotherapy Association (2017)online available at http://www.wcpt.org/node/24012* [Online]. [Accessed 14/03 2018].
World Health Organisation. 2001. *International classification of functioning, disability and health* [Online]. Available: http://www.who.int/classifications/icf/en/ [Accessed 16 August 2013].
World Health Organisation. 2007a. *International classification of functioning, disability and health: children and youth version: ICF-CY available at https://apps.who.int/iris/handle/10665/43737* [Online]. Geneva. Available: https://apps.who.int/iris/handle/10665/43737.
World Health Organisation 2007b. Introductory chapter page XV. *International classification of functioning, disability and health: children and youth version: ICF-CY available at https://apps.who.int/iris/handle/10665/43737*. Geneva.
World Health Organization 2013. Multi-country assessment of national capacity to provide hearing care. *Geneva: World Health Organization*.
World Health Organization. 2016. *Global Strategy for Women's, Children's and Adolescents' Health, 2016-2030* [Online]. Available: http://www.who.int/life-course/partners/global-strategy/global-strategy-2016-2030/en/ [Accessed 26/09 2017].
World Health Organization & Unicef 2009. WHO child growth standards and the identification of severe acute malnutrition in infants and children: a joint statement by the World Health Organization and the United Nations Children's Fund. Geneva: World Health Organization.
World Health Organization, Unicef & World Bank Group. 2018. *Nurturing care for early childhood development: a framework for helping children survive and thrive to transform health and human potential available at https://apps.who.int/iris/bitstream/handle/10665/272603/9789241514064-eng.pdf* [Online].
World Health Organization & World Bank. 2011a. *World report on disability* [Online]. Geneva WHO. Available: http://www.who.int/disabilities/world_report/2011/en/index.html [Accessed 19/12 2013].
World Health Organization & World Bank 2011b. World Report on Disability. Geneva: WHO.
Yang, X. 2015. No matter how I think, it already hurts: Self-stigmatized feelings and face concern of Chinese caregivers of people with intellectual disabilities. *Journal of Intellectual Disabilities*.
Young Lives August 2008. Children's well-being in Contexts of poverty: Approaches to Research, Monitoring and participation. *Young lives technical note No.12*
Yousafzai, A. K., Farrukh, Z. & Khan, K. 2011. A source of strength and empowerment? An exploration of the influence of disabled children on the lives of their mothers in Karachi, Pakistan. *Disability and rehabilitation,* 33**,** 989-998.
Yousafzai, A. K., Lynch, P. & Gladstone, M. 2014. Moving beyond prevalence studies: screening and interventions for children with disabilities in low-income and middle-income countries. *Archives of disease in childhood***,** archdischild-2012-302066.

Zhang, Y., Subramaniam, M., Lee, S. P., Abdin, E., Sagayadevan, V., Jeyagurunathan, A., Chang, S., Shafie, S. B., Rahman, R. F. A. & Vaingankar, J. A. 2018. Affiliate stigma and its association with quality of life among caregivers of relatives with mental illness in Singapore. *Psychiatry research,* 265**,** 55-61.

Zuurmond, M., Banks, L. M., Monteath–Van Dok, A., Gallinetti, J. & Singal, N. 2019. Perspectives of children with disabilities and their guardians on factors affecting inclusion in education in rural Nepal:"I feel sad that I can't go to school". *Oxford Development Studies,* 47**,** 289-303.

Zuurmond, M., Mahmud, I., Polack, S. & Evans, J. 2015. Understanding the Lives of Caregivers of Children with Cerebral Palsy in rural Bangladesh: Use of Mixed Methods. *Disability, CBR & Inclusive Development,* 26**,** 5-21.

Zuurmond, M., Nyapera, V., Mwenda, V., Kisia, J., Rono, H. & Palmer, J. 2016. Childhood disability in Turkana, Kenya: Understanding how carers cope in a complex humanitarian setting. *African journal of disability,* 5.