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## **Children with cerebral palsy in Ghana: malnutrition, feeding challenges and caregiver quality of life**

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## **Abstract**

**Aim:** To assess feeding difficulties and nutritional status among children with cerebral palsy in Ghana, and assess the relationship between these variables and caregiver quality of life.

**Methods:** This cross-sectional survey included 76 children with cerebral palsy (18 months to 12 years) from four regions of Ghana. Severity of cerebral palsy was classified using the Gross Motor Function Classification System and anthropometric measures were taken. Caregivers rated their quality of life (PedsQL™ Family Impact questionnaire Module) and difficulties with eight aspects of child feeding. Regression analysis explored factors associated with being underweight and the relationship between caregiver quality of life and child malnutrition and feeding difficulties.

**Results.** The prevalence of malnutrition was very high: 65% of children aged <5 years were categorised as underweight, 54% as stunted and 58% as wasted. Reported difficulties with child's feeding were common and was associated with the child being underweight (Odds Ratio 10.7 95% CI 2.3-49.6) and poorer caregiver quality of life ( $p < 0.001$ ). No association between caregiver quality of life and nutritional status was evident.

**Interpretation:** There is a need for appropriate, accessible caregiver training and support around feeding practises of their children with cerebral palsy, to improve child nutritional status and caregiver well-being.

What this paper adds:

- Malnutrition is very common among children with cerebral palsy in Ghana.
- Feeding difficulties in this population were strongly associated with being underweight
- Feeding difficulties were associated with poorer caregiver quality of life
- Child nutritional status was not associated with caregiver quality of life

Cerebral palsy is a common cause of physical disability in children<sup>1</sup> and evidence suggests that children with cerebral palsy are particularly vulnerable to malnutrition.<sup>2</sup> Reasons for this include physiological factors such as dysregulation of growth hormone secretion and muscle spasticity.<sup>3</sup> Feeding difficulties, including oral-motor impairments affecting chewing, food ingestion and self-feeding, are common and often severe.<sup>4,5</sup> These difficulties may negatively impact the responsiveness of caregiver feeding practises, further reducing nutritional intake.<sup>6</sup> The right to food is enshrined into various Human Rights charters, however the nutritional needs of children with disabilities are rarely addressed.<sup>7</sup> In low resource settings additional challenges around poor 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 cerebral palsy in these settings.

As well as the likely association with poor nutritional status, child feeding difficulties may negatively impact caregiver well-being.<sup>8</sup> Research has highlighted negative experiences and stress associated, for example, with drooling, choking and the high level of assistance required to support children with cerebral palsy.<sup>8,9</sup> Few studies have specifically explored the impact of feeding difficulties in children with cerebral palsy on caregiver quality of life. This deserves attention in terms of the delivery and impact of appropriate interventions supporting both children with cerebral palsy and their caregivers.

The aims of this study were to assess feeding difficulties and nutritional status among children with cerebral palsy in Ghana, and to assess the association between these variables and caregiver quality of life.

## Methods

This article reports on a survey conducted as part of an evaluation to assess the impact of a parent training programme for carers of children with cerebral palsy. The study was conducted in eight sites in Ghana: across the Upper East, Greater Accra, Brong Ahafo and Ashanti regions.

### *Study participants*

Caregivers and children with cerebral palsy were recruited through Community Based Rehabilitation screening programmes (n=46), physiotherapists record review (n=22) and community screening in one area (n=8). Cerebral palsy was identified as a diagnosis by a qualified clinician (developmental paediatrician or physiotherapist). Eligibility criteria were confirmed diagnosis of cerebral palsy 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. The target for the evaluation study was to include eight training groups of 8-10 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-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 cerebral palsy, feeding difficulties, reported health status and anthropometry) and their primary caregivers (socio-demographic and economic characteristics and quality of life). 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 cerebral palsy was assessed using the Gross Motor Function Classification System<sup>10</sup>, an internationally-recognised system, which classifies cerebral palsy according to 5 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.<sup>8</sup> Eight questions were asked about frequency of difficulties with different aspects of eating and drinking (e.g. How often is it a problem that your child coughs or chokes whilst eating or drinking?) rated on a five-point scale from 'never' to 'always'.

Caregiver and family quality of life (QoL) was assessed using the PedsQL™ Family Impact questionnaire Module designed to measure the impact of paediatric conditions on parents and the family.<sup>11</sup> It consists of 36 items across six sub-scales: self-reported physical, emotional, social, and cognitive functioning, communication and family, daily activities and family relationships. Each item is measured on a 5-point response scale (“never a problem” to “always a problem”). This tool was translated using linguistic validation guidelines which included forward and backward translation and field testing for each language to check on cognitive understanding.

Anthropometric measures were taken using standardised protocols adapted for use in the field. Where possible, standing height was measured for children > 5 years and recumbent length was taken for children <5 years, both measured to nearest 0.1cm. Knee height<sup>12</sup> (CLPR65 Anthropometric Caliper, MediForm, Oregon, USA) was recorded for all children to the nearest 0.1cm. Following WHO best-practice procedures<sup>13</sup>, 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 <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, TALC). 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.

### *Statistical Analysis*

For the purposes of analysis the GMFCS was reclassified into three groups: mild (levels I and II), moderate (levels III) and severe (levels IV and V). We generated a composite feeding score comprised of the eight questions which ranged from 0 (extreme difficulties) to 100 (no difficulties). We assessed the internal consistency of this composite scale by checking that cronbach’s alpha coefficients were >0.7 and item-total correlations were >0.3 as per recommended guidelines for reliability.<sup>14</sup> The composite score was divided into tertiles. A socioeconomic status (SES) index was calculated from poverty indicators using principal components analysis and divided into tertiles.

It was not possible to measure the standing height of 16 of the children aged ≥5 years and the recumbent length for three children <5 years. For these children, knee height was used a proxy measure. The line of best fit on a scatter graph of the relationship between laying length and knee height was used to predict the heights of those children for whom data were unobtainable. We used this method because of a lack of validated published formulae (for converting knee height to standing height) available for this specific study population. Weight-for-age (children <10 years

only), height-for-age and weight-for-height (children  $\leq 5$  years only) z scores were calculated based on WHO growth standards using the Emergency Nutrition Assessment<sup>15</sup> and WHO Anthroplus software. Children with z scores between -2 and -3 were defined as moderately stunted/wasted/underweight and those with z scores  $< -3$  were defined as severely stunted/wasted/underweight. For MUAC, wasted was defined as 115mm – 124mm and severe wasting as  $< 115$ mm. Children with extreme z-score values (z-scores greater than 5 or 6/less than -5 or -6, depending on the measure) were excluded from the analysis as per standard guidelines – these being more likely due to error than real extreme values (n=6).<sup>16</sup>

We used the PedsQL Family Impact Module Total Scale Score for analyses, which is calculated as the sum of all 36 items divided by the number of items answered.<sup>11</sup> These scores were converted into scores out of 100 (0 as the worst possible score and 100 as the best score).

Multivariate logistic regression was undertaken to explore factors (socio-economic characteristics, severity of cerebral palsy and feeding difficulties) associated with being underweight. Underweight (weight-for-age z score) 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. 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, SES and cerebral palsy severity). For these analyses, QoL life data were transformed (square root) because the data were skewed.

#### *Ethical Considerations*

Ethics approval was obtained from the London School of Hygiene and Tropical Medicine and from The Noguchi Memorial Institute for Medical Research, College of Health Sciences, University of Ghana. Written informed consent was obtained from all caregivers. 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 (table 1). The majority of children were under 5 years (72%) and mean age was 3.8 years (95% CI 3.2- 4.5). There were 47% females in the sample. The majority of children had severe cerebral palsy: 25% were classified as having GMFCS level V, 28% with level IV, 25% III, 14% as level II and 8% as level I. Of the 37 children of pre-school/school age, only 10 (26%) were currently enrolled in school and 11 (29%) had ever attended school. Caregivers were nearly all female (97%) and the vast majority were mothers (80%) or grandparents (15%). The majority of caregivers (61%) reported not having worked 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*

Difficulties with the child's feeding were commonly reported (figure 1). More than half the caregivers reported their child experienced feeding problems at least 'sometimes' in all eight domains. The majority of caregivers (75%) reported their child 'always' needed help with feeding. Two thirds of caregivers reported 'always' worrying about their child's feeding and 50% '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 (SD 31.7) out of a highest possible score ('no difficulties') of 100.

### *Prevalence of Malnutrition*

A high proportion of the children in this sample were categorised as malnourished (table 2): 65% of children aged <5 years were underweight, 54% as stunted and 58% as wasted. Including the older children, 56% were stunted and 63% (<10 years only) were underweight. All mean z scores were below -1.8. We conducted a sensitivity analysis, 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 3, the risk of being underweight was significantly higher among children experiencing the greatest difficulties with feeding (i.e. in the highest feeding score tertile: 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%) cerebral palsy, 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 3.

#### *Caregiver and family quality of life*

Caregiver QoL scores in this study population were low: the median summary total score was 12.5 (SD 18.7) out of a maximum score of 100 (highest QoL). Median summary scores for the sub-scales ranged from 0 (SD 24.9) for daily activities to 16.7 (SD 21.8) for physical functioning.

Quality of life scores were significantly lower among caregivers whose children had the greatest difficulties with feeding (median score 11.5 Standard Deviation (SD) 24.3) compared to those with least difficulties (30.2 SD 10.2,  $p=0.01$ ) even with adjustment for potential confounders. QoL was similar for caregivers with a child with cerebral palsy who was underweight (11.8 SD16.2) compared to caregivers whose child was not underweight (11.1 SD 16.2,  $p=0.14$ ).

## Discussion

The prevalence of malnutrition in this population of children with cerebral palsy from rural Ghana was very high. Caregiver-reported difficulties with child's feeding were common and greater feeding difficulties was strongly associated with the child being underweight. Feeding difficulties, but not the presence of malnutrition, were also significantly associated with poorer caregiver QoL.

Approximately two-thirds of this study population were malnourished and over a third of was severe. 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.<sup>17</sup> Similarly 58% were wasted and 54% were stunted compared to the national average of 5% and 19% respectively.<sup>17</sup>

These findings support previous studies highlighting that malnutrition is common among children with cerebral palsy. The prevalence in the current study was higher than previously reported in both high and low income settings.<sup>2</sup> A recent study in Uganda, for example, which used the same growth reference standards, found that 52% of children with cerebral palsy were malnourished, with underweight being the most common category at 42%.<sup>18</sup> The lower prevalence in the Uganda study may be partly attributed to the lower proportion of the study children with severe cerebral palsy (53% in Ghana, 33% in Uganda). Furthermore the children were all attending a paediatric cerebral palsy 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 WHZ (57%). This discrepancy has been previously noted for children with cerebral palsy.<sup>18</sup> 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.<sup>19</sup> One possible reason for the discrepancy could be that children with cerebral palsy mobilise more with their arms and thus MUAC is built up more than in other children. However, given that: all the other anthropometric indicators of malnutrition are strikingly high in this population and underlying disability is a major risk factor for death among malnourished patients,<sup>20</sup> it could be argued that automatic referral of all children with cerebral palsy 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).<sup>21</sup>

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 cerebral palsy and malnutrition.<sup>2</sup>

Malnutrition was common even among children with mild and moderate cerebral palsy and arguably higher than might be 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 practises.

Greater feeding difficulties were associated with poorer caregiver QOL. This aligns with previous research showing that feeding difficulties can be stressful for carers, with reasons including the feeding experience<sup>8</sup> itself as well as the extra money and time required.<sup>22</sup> 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 cerebral palsy 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 cerebral palsy in Ghana and contributes to the overall lack of empirical data on this topic from low income countries. We used a standardised questionnaire and common anthropometric assessment methods.

There were some limitations. The sample size was relatively small and therefore some caution is warranted in interpreting the findings. We did not include a control population without cerebral palsy against which to compare findings or assess additional factors that may affect child nutritional status, such as dietary intake, which deserves attention in future studies. Most children were identified through community programmes/screening in rural areas and therefore findings may not be generalisable to wealthier urban areas.

Height measurement is challenging and particularly among children with cerebral palsy 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 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. Some previous studies have used cerebral palsy growth reference curves, but these are out-dated, 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 cerebral palsy.<sup>23</sup> Finally, we acknowledge the discrepancy between acute malnutrition as assessed by MUAC and by WHZ which has also been observed in other populations.<sup>24</sup> 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.<sup>25</sup>

### *Conclusion*

The prevalence of malnutrition among children with cerebral palsy 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 practises of their children with cerebral palsy, both to improve child nutritional status and the well-being of their caregivers. Further research on anthropometric assessment for children with cerebral palsy is also needed.

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**Figure 1** – Caregiver reported difficulties with child’s feeding (caregivers were asked how often these aspects of feeding were a problem).

**Table 1:** Socio-demographic characteristics of the children with cerebral palsy and their caregivers

	N	%
<b>Child Variables</b>		
<b>Sex</b>		
Male	41	54%
Female	35	46%
<b>Age Group</b>		
18months-2 years	31	41%
3-4 years	23	31%
5+ years	21	28%
<b>Region</b>		
North	40	53%
South	36	47%
<b>Cerebral Palsy Severity</b>		
I (mild)	6	8%
II (mild)	11	14%
III (moderate)	19	25%
IV (Severe)	21	28%
V (severe)	19	25%
<b>Caregiver/household variables</b>		
<b>Age group</b>		
<30	23	30%
30-40	34	45%
40-60	15	20%
60+	4	5%
<b>Relationship to child</b>		
Mother	61	80%
Father	1	1%
Grandparent	11	15%
Other	3	3%
<b>Worked in last month</b>		
No	46	61%
Yes	30	39%
<b>Marital status</b>		
Married/living together	53	70%
Divorced/separated	6	8%
Widowed	6	8%
Single	11	15%
<b>Ever attended school</b>		
No	33	43%
Yes	43	56%
<b>Highest level completed</b>		
None	33	43%
Primary	18	24%
Junior High	13	17%
Senior High	9	12%
Tertiary	3	4%

**Table 2** Prevalence of malnutrition and mean z scores

	<b>All ages<sup>a</sup></b>		<b>Children &lt;5 years</b>	
	N	% (95% CI)	N	% (95% CI)
<b>Weight for Age</b>				
'Normal' ( WAZ $\geq 2$ )	24	37% *(25.8-49.5)	17	35% (22.8-50.3)
Underweight ( $\geq -3$ 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)
<i>Mean WAZ (95% CI)</i>		-2.6 (-3.0- -2.2)		-2.5 (-3.0- -2.1)
<b>Height for Age</b>				
'Normal' ( HAZ $\geq 2$ )	29	41% (29.8-52.9)	24	46% (32.8-60.1)
Stunted ( $\geq -3$ 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)
<i>Mean HAZ (95% CI)</i>		-2.3 (-2.6- -1.9)		-2.1 (-2.5- -1.7)
<b>Weight for height</b>				
'Normal' ( WHZ $\geq 2$ )			20	42% (28.3-56.4)
Wasted ( $\geq -3$ to $<2$ )			16	33% (21.1-48.2)
Severely wasted ( $<-3$ )			12	25% (14.5-39.6)
<i>Mean WHZ (95% CI)</i>				-1.9 (-2.3 - -1.5)
<b>Middle Upper Arm Circumference</b>				
'Normal' ( $\geq 125$ mm)			43	80% (66.4-88.9)
Wasted (115-124mm)			10	19% (10.1-31.2)
Severely wasted ( $<115$ mm)			1	1% (0-13)
<i>Mean MUAC (95% CI)</i>				143.0 (127.2-128.8)

<sup>a</sup>Weight for age calculated for children <10 years as per guidelines. WAZ= Weight for Age Z score; HAZ=Height for Age Z score; WHZ=Weight for Height Z score; MUAC=Middle Upper Arm Circumference

**Table 3:** Association between underweight and socio-demographic, clinical and feeding variables among children aged under 10 years

	N	Number underweight (%)	Age and Sex adjusted odds Ratios (95% CI)
<b>Child variables</b>			
<b>Age</b>			
18months-2yrs	28	21 (75%)	1.6 (0.4-5.8)
3-4 years	20	10 (50%)	0.6 (0.2-2.3)
5+ years	16	10 (63%)	Reference
<b>Sex</b>			
Male	36	23 (65%)	Reference
Female	28	18 (65%)	1.1 (0.4-3.1)
<b>CP severity</b>			
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)
<b>Epilepsy</b>			
No	44	28 (64%)	Reference
Yes	19	13 (68%)	1.5 (0.5-5.0)
<b>Serious health problem in past 12 months</b>			
No	11	65%	Reference
Yes	33	65%	0.9 (0.3-3.1)
<b>Feeding difficulties</b>			
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) <sup>a</sup>
<b>Caregiver/Household variables</b>			
<b>Age</b>			
<30 years	20	13 (65%)	1.1 (0.3-5.0)
30-40 years	30	20 (67%)	1.6 (0.4-6.3)
>40 years	14	8 (57%)	
<b>Education</b>			
None	27	19 (70%)	Reference
Some	37	22 (59%)	0.8 (0.3-2.3)
<b>Socio-economic status</b>			
Least poor	21	12 (57%)	
Medium	19	11 (53%)	1.0 (0.3-3.6)
Poorest	23	18 (78%)	2.7 (0.7-10.6)

<sup>a</sup> Remained independently associated with being underweight with adjustment for all other variables (as potential confounders) included in the table.