Using in-depth interviews and participatory visual methodologies to investigate healthcare access among adults with disabilities in Brazil.

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Declaration

I, Veronika Reichenberger, confirm that the work presented in this thesis is my own. Where data and information have been derived from other sources, I confirm that these have been indicated in the thesis.

Student signature: [redacted]

Date: 27/03/2024

Abstract

Background: People with disabilities face inequalities in many areas of life, including their frequent experience of barriers to accessing healthcare services. The Zika epidemic revealed gaps in the Brazilian healthcare system for children with disabilities, however, evidence is lacking on adults with disabilities accessing the healthcare system. Additionally, people with disabilities may face exclusion in research. Participatory Visual Methodologies, especially with the use of videos, can empower individuals, facilitate communication, promote inclusivity, and actively participate in research concerning them, but have rarely been used with people with disabilities. This thesis broadens the understanding of healthcare access for people with disabilities in Brazil by also examining relevant contexts in Latin America and the Caribbean and exploring the experiences of caregivers of children affected by Zika in Colombia. These regional insights enrich the overall analysis and contribute to a more comprehensive understanding of the barriers and facilitators to healthcare access in Brazil.

Study Aim: The study aim was to understand healthcare access in Brazil from both a broad and zoomed in perspective, involving people with disabilities, as well as exploring more accessible ways to engage people with disabilities in research.

Methods: The aim will be achieved through these objectives: To systematically review the literature to understand barriers and facilitators to primary healthcare access among adults with disabilities in Latin America and the Caribbean; Investigate barriers and facilitators to primary healthcare access among adults with disabilities in Brazil, using in-depth interviews; Explore the feasibility of using participatory visual methodologies in disability research; Explore the use of Participatory Video as a method in health research involving people with disabilities.

Key findings: The systematic review highlighted healthcare access barriers such as urban infrastructure, attitudinal barriers, and inaccessible health information for people with different impairments. The in-depth interviews and Participatory Video supported the findings from the systematic review. The Participatory Video led to a better involvement of people with different disabilities in the study, providing different means of expression, it enriched the findings, led to social change and empowerment through data collection and dissemination. Using participatory visual methods supported data collection to involve people in different ways, both in the process as well as the impact during dissemination, and it was both feasible and acceptable.

Conclusion: People with disabilities in Brazil have a good understanding of their healthcare needs, however, there are barriers that get in the way of those needs being met, and the use of visual methods supports an in-depth understanding of these challenges.

Format of Thesis

This thesis consists of four research papers and three linking chapters.

Chapter One: An introduction to disability, healthcare access and Participatory Visual Methodologies. This chapter describes the realms of health and disability, examining the conceptualization of disability. It explores the intricate connection between disability and access to healthcare. Furthermore, a comprehensive overview is provided regarding disability and healthcare access for adults in Brazil. The chapter also introduces participatory visual methodologies and the creation of Participatory Videos involving individuals with disabilities.

Chapter Two, Methodology: Within this chapter, the emphasis lies in delineating the objectives and aims of this doctoral study. The Levesque framework, employed to conceptualize healthcare access across various sections of this PhD, is introduced. Furthermore, the Participatory Ladder is explained, and a thorough explanation is provided for the qualitative data collection and analysis methods. The chapter concludes with my reflectivity statement.

Chapter Three, Paper One: Access to primary healthcare services for adults with disabilities in Latin America and The Caribbean; a review and meta-synthesis of qualitative studies. This chapter presents a systematic review of peer-reviewed qualitative literature on healthcare access among adults with disabilities in Latin America and The Caribbean. It presents the findings of the main barriers people with disabilities face in accessing primary healthcare services.

Chapter Four, Paper Two: Access to primary healthcare services: the perspective of adults with disabilities in Brazil. This article presents the results of a qualitative study that elucidates the obstacles and enablers in accessing primary healthcare services for adults with disabilities in three regions of Brazil: Pernambuco (Arcoverde), São Paulo (Santos and São Paulo) and Distrito Federal (Brasília).

Chapter Five, Paper Three: Participatory visual methods with caregivers of children with congenital Zika syndrome in Colombia. This paper explores the acceptability and feasibility of gathering information on the experiences and perspectives of carers of children with congenital Zika syndrome using two different participatory visual methods: Digital Storytelling and Participatory Video. The paper describes the experience of caregivers of children with disabilities in Colombia who took part in both processes.

Chapter Six, Paper Four: Enhancing Disability Research Through Participatory Video: Reflections on a Brazilian Study. This chapter documents the process of using Participatory Video with adults with disabilities in Arcoverde, Pernambuco, Brazil, to understand barriers and facilitators to access healthcare services.

Chapter Seven: Discussion and conclusion. In this chapter, the study's findings are examined and discussed, while also reflecting on the application of participatory visual methodologies with people who have disabilities.

The appendices encompass supplementary materials that support the published papers.

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List of Abbreviations

HDI	**Human Development Index**
ICF	**International Classification of Functioning, Disability and Health**
ICED	**International Centre for Evidence in Disability**
LMIC	**Low and middle-income countries**
PAHO	**Pan American Health Organization**
PNSPCD	**National Health Policy for Persons with Disabilities**
OPDs	**Organization of Persons with Disabilities**
PAR	**Participatory Action Research**
PV	**Participatory Video**
PVM	**Participatory Visual Methods**
SDGs	**Sustainable Development Goals**
SUS	**Sistema Único de Saúde**
UN	**United Nations**
UHC	**universal health coverage**
UNCRPD	**UN Convention on the Rights of Persons with Disabilities**
WHO	**World Health Organization**

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Chapter One: An Introduction to disability, healthcare access and participatory visual methodologies

1.1 Disability and Healthcare

Within this section, I delve into the realms of health and disability, examining the interconnection between the two, and exploring the conceptualization of disability.

1.1.1 Health and human rights

Established in 1948, the World Health Organization (WHO) declared healthcare to be an inherent human right and defined health as “a state of complete physical, mental and social well-being” [1]. The United Nations (UN) strengthened this commitment through a broad range of actions, including when they established their Sustainable Development Goals in 2015. Goal 3 of the Sustainable Development Goals (SDGs) focuses on ensuring healthy lives and promoting well-being for all at all ages. The goal is to ensure access to quality healthcare services, promote mental health, and prevent and treat diseases. It encompasses a wide range of targets, including reducing maternal and child mortality, ending the epidemics of AIDS, tuberculosis, malaria, and other communicable diseases, as well as ensuring universal access to sexual and reproductive healthcare services. Goal 3 aims to create a world where everyone can lead a healthy and fulfilling life, irrespective of their age or background. It recognizes the interconnectedness of health and well-being with other development goals and emphasizes the importance of a holistic approach to healthcare [2]. Through collective action from member countries, we can ensure that every individual has access to quality healthcare—their basic human right. The goal of this PhD is to increase knowledge on healthcare access in Brazil to improve access to healthcare services for all, as outlined in target 8. Target 8 of Goal 3 of the Sustainable Development Goals (SDGs) is specific to achieving Universal Health Coverage (UHC). The target is as follows:

> "Achieve universal health coverage, including financial risk protection, access to quality essential healthcare services, and access to safe, effective, quality, and affordable essential medicines and vaccines for all."

This target underscores the commitment to ensuring that everyone, regardless of their economic status or health status, has access to essential healthcare services without facing financial hardship. UHC involves providing a full range of health services, including prevention, treatment, rehabilitation, and palliative care, and ensuring that these services are of high quality and affordable and available to all.

Achievement of UHC necessitates the creation of a healthcare system that leaves no one behind, addressing the health needs of all individuals and communities without causing financial difficulty. Achieving UHC is crucial for promoting well-being, reducing poverty, and contributing to overall sustainable development. UHC encompasses preventive care, curative services, and palliative solutions. Regrettably, a staggering 400 million people worldwide are deprived of healthcare services [3]. Countless individuals from vulnerable or marginalized groups face even grimmer prospects due to their age, gender, socioeconomic status, ethnicity, sexual orientation and disability [3]. Consequently, these populations have an increased risk of exclusion when accessing essential care.

Ensuring accessible healthcare services for individuals with disabilities is crucial for achieving UHC for all, upholding their rights [4]. This commitment also contributes to reducing morbidity, mortality and poverty [5]. However, currently efforts to achieve UHC are leaving people with disabilities behind. For instance, a recent extensive study in Afghanistan revealed that investments in UHC yielded minimal or no improvement in services for people with disabilities [6]. Research findings from Chile and Greece indicate that health system reforms geared towards UHC may have unintentionally shifted the focus from human rights indicators to economic ones, leaving individuals with disabilities at a disadvantage in healthcare access [7]. This evidence emphasizes the importance of directing specific attention to people with disabilities.

One of the main obstacles to making UHC strategies more inclusive of people with disabilities is the scarcity of evidence on the necessary and effective measures. Current tools for monitoring UHC tend to be relatively general, emphasizing coverage over access, making them unsuitable for identifying the additional needs of individuals with disabilities [8]. There is a need for further research to pinpoint the gaps and viable solutions in achieving UHC for people with disabilities. Complicating matters, diverse barriers and challenges exist in different settings and for different types of impairments, highlighting the need for locally tailored solutions available to all who need them. Adhering to the key slogan of the Disability Movement, "Nothing about us, without us," it is imperative to involve people with disabilities in the design of these strategies to ensure their feasibility and acceptability [4]. This is a gap this study aims to fulfil, collecting more data on disability and healthcare access through different methods of engaging people with disabilities and their carers.

1.1.2 Disability

Globally, at least 1.3 billion people are living with a disability, 16% of the world's population, the majority of whom reside in low and middle-income countries (LMIC) [9]. The prevalence of disability increases with age, and is commonly linked to poverty, with consequences including exclusion from education, employment and general participation [3].

Over time, models used to understand disability have been re-examined. In response to the medical model, which paints those with disabilities as defined by individual health needs needing resolution, disabled people's movement and social scientists proposed the social model. This perspective advocates that disability is actually caused by society's failure to provide support and accommodate for their needs [10]. Essentially, it is not a person's impairment itself disabling them - but our inability to make accommodations in its stead [3]. The International Classification of Functioning, Disability and Health (ICF) - otherwise known as the "bio-psycho-social model" [3] – is the framework I will be utilizing, because it is the WHO's way of resolving the conflict between the medical and social models. Consistent with this perspective, the UN Convention on the Rights of Persons with Disabilities (UNCRPD) (2006) states that persons with disabilities includes those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others [11]. This concept recognizes that disability and functioning are a result of an intricate interplay between health conditions, individual elements and environmental factors alike [3]. The WHO's ICF model consists of three main components:

- Body Functions and Structures: This component addresses the physiological functions of the body and the anatomical structures. It covers functions such as mobility, communication, and mental functions, as well as structures like organs and limbs.
- Activities and Participation: This component focuses on the individual's ability to engage in activities and participate in various life situations. It includes domains such as self-care, mobility, communication, and interpersonal interactions.
- Environmental Factors: These factors comprise the surroundings where individuals reside and navigate their daily existence, encompassing the physical, social, and attitudinal dimensions. This incorporates aspects like building accessibility, social support, and societal perspectives.

Each of these three components is influenced by environments. The ICF model offers a shared vocabulary for articulating matters related to health and health-related conditions, making it useful for health professionals, policymakers, and researchers. Overall, the ICF promotes a more holistic and inclusive approach to understanding health.

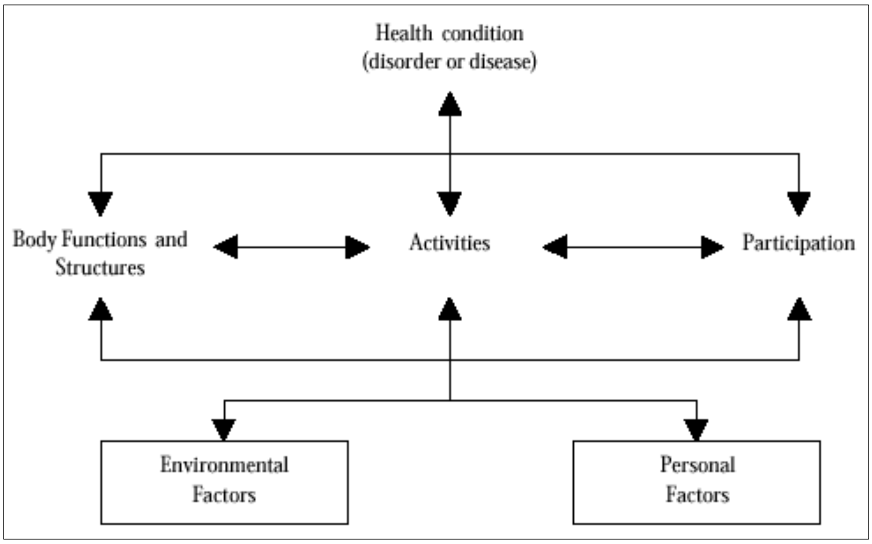

Figure 1: *International Classification of Functioning, Disability and Health* (ICF) [3]

1.1.3 Disability and access to health

Although individuals with disabilities are confronted with the same general healthcare requirements as their non-disabled peers, they also have specific medical needs that often go unaddressed. Consequently, people with disabilities are at an increased risk of ill-health and underlying health conditions [9, 12, 13]; they tend to report poorer overall health than people without a disability [7, 14], and are more likely to suffer from chronic issues like obesity, hypertension, and mental illnesses [15-20]. Unfortunately, people with disabilities have an elevated risk of being unemployed [21]. In turn, this then leads to poor physical and mental health outcomes [22, 23] and issues such as inadequate diets, unhealthy living conditions, and limited access to basic resources [24, 25]. Accessing primary healthcare is essential for ensuring early intervention care, managing chronic conditions, and providing health promotion opportunities. It may be the only port of call to a professional when people do not have access to secondary of tertiary care. Furthermore, it is an important gateway to specialized services that many people with disabilities will require (such as ophthalmology, assistive technology and physiotherapy) [26].

Compounding these challenges, individuals with disabilities face higher healthcare expenditures, being 50% more likely to encounter catastrophic health expenses. Moreover, the quality of care provided to them is consistently reported as poorer [27-29]. There may be barriers in healthcare delivery. Consequently, this marginalized group is falling behind in critical components of Universal Health Coverage (UHC), emphasizing the urgent need for targeted interventions to address these multifaceted health disparities.

Exclusion from healthcare is a violation of rights, as set out by the UNCRPD and the laws of most countries. According to the UNCRPD, there must not only be physical and structural changes made for those with disabilities but also equal access to experience and knowledge as their non-disabled counterparts [11]. The Convention further specifies every individual's right to free or low-cost health services without discrimination (Articles 25 & 26) [11]. Ensuring equitable access to healthcare for people with disabilities is crucial not only to uphold fundamental rights but also to pave the way for the realization of UHC.

1.1.4 Disability and healthcare access barriers

People with disabilities have greater difficulties accessing healthcare, despite their greater average needs. Research shows there are widespread barriers to healthcare access shared by many: inadequate affordability, physical inaccessibility of facilities and equipment, insufficient communication methods for those who need it most; as well as undertrained professionals and unfavourable attitudes towards disability [12]. People with disabilities often experience a lack of financial resources, which can impede their access to vital services. This disparity is reflected in the fact that upwards of 51-53% of disabled individuals are unable to receive necessary healthcare due to cost concerns compared to only 32-33% who do not have disabilities [3]. Moreover, transportation expenses add an additional challenge for those seeking medical care, as lack of accessible transportation means people with disabilities need to reply on private transportation services [30]. Besides the affordability of transportation, accessibility to healthcare services may also be restricted due to availability and mileage. Physical inaccessibility presents a huge hindrance as well; often healthcare centres lack wheelchair ramps, have tight entrances, do not provide suitable restrooms nor contain adapted apparatus. All these issues contribute to reduced access [3, 31, 32].

In addition to these barriers, there are also communication issues that can impede access to health promotion and prevention information, such as inadequate signage in hospitals, limited easy-read material featuring symbols or images, no sign language interpreter available or unavailability of braille resources [33]. Consequently, those with sensory, cognitive or psychosocial impairments find it hard to understand and take advantage of preventative healthcare measures which could have reduced chronicity, comorbidities and late diagnosis [3, 31, 32]. A scarcity of information about potential healthcare options and alternatives can obstruct patients from receiving more tailored advice during their appointments [3]. Healthcare providers' lack of skills and understanding, combined with pervasive negative attitudinal issues, create barriers that prevent people from accessing health care. Stigma leads many individuals living with disabilities to anticipate that they will be refused service or treated unfairly when attempting to access healthcare services [3, 34-36]. Research also indicates that people with disabilities attend fewer routine health examinations than their non-disabled counterparts [37] and are less likely to receive preventive care overall [18, 38-41]. Individuals living with disabilities are significantly more likely to face mistreatment, disallowance of care and inadequate healthcare professionals that lack the necessary skills for their condition [33]. In fact, data from four countries in Southern Africa reveal that less than half of persons with disabilities were provided medical rehabilitation services when needed whereas fewer still - a third or less - received essential assistive devices such as wheelchairs, prostheses and hearing aids [3]. The World Health Survey has revealed that adults with disabilities are far less likely to receive the medical attention they need, when compared to those without impairments [3].

Unveiling the complexity of barriers in access to healthcare involves two critical aspects: how data is collected and by whom. For evaluating success of healthcare, quantitative impact evaluations are relevant; for understanding how people are excluded, qualitative approaches are most suitable. And yet, we can also look for more inventive approaches to explore these concepts even further. Participatory visual methodologies are potentially advantageous as they allow individuals to comprehend complex topics and perspectives more effectively than simple descriptions [41]. This approach not only highlights the importance of understanding but also eliminates potential restrictions when trying to communicate ideas.

1.2 Brazil: An overview on disability and health

To understand healthcare access for people with disabilities in Brazil, it is essential to consider the broader policy context within Latin America and the Caribbean. Countries in this region have diverse healthcare systems with varying degrees of accessibility and inclusivity for people with disabilities. Many of these countries face challenges such as insufficient healthcare infrastructure, limited funding, and significant disparities in healthcare access between urban and rural areas [42]. Additionally, the cultural and socio-economic differences across the region impact the implementation and effectiveness of disability-related policies [3]. Research in Latin America has shown that people with disabilities often face barriers to healthcare, including financial difficulties, inadequate infrastructure, and a lack of specialised services [43]. In countries such as Colombia, studies have found that people with disabilities encounter obstacles in accessing necessary treatments, reflecting broader systemic issues within healthcare delivery. Similarly, in the Caribbean, fragmented healthcare systems have been linked to difficulties in providing consistent and comprehensive services for people with disabilities [44]. Understanding these regional challenges provides valuable context for examining the specific situation in Brazil and highlights the need for comparative research across the region to develop more effective strategies for improving healthcare access for people with disabilities. Brazil is a Latin American country characterised by its vast population, numbering approximately 217 million individuals [45]. Brazil is middle income - In the global context, Brazil holds the 87th position among 189 countries according to the Human Development Index (HDI). When focusing specifically on the HDI rankings of 33 Latin America and the Caribbean states, Brazil stands as the 16th in the hierarchy [46].

In the 53rd meeting of Pan American Health Organization (PAHO) member states in 2014, the Latin American member countries agreed to strengthen their healthcare systems to achieve UHC [7]. The strategy suggested by PAHO to reach UHC was to achieve four aspects: accessible, integral and quality healthcare services; effective governance of the health system; sufficient and stable investment in healthcare, with the public spending in health of at least 6% of the GDP; and act upon social and environmental determinants of health [47]. Brazil has seen a move towards UHC, resulting from its pioneering stance in Latin America in making access to healthcare a constitutional right [48]. Brazil has been progressing on its efforts towards UHC even before the agreement between PAHO members, due to Brazil's national health system, Sistema Único de Saúde (SUS), which was developed in 1988, after the fall of an authoritarian military dictatorship [49]. SUS has contributed to an improvement in human rights and the reduction of social inequalities, as well as positively impacting the health of Brazilians [50]. One of the pillars of SUS is 'equity', which is a social justice principle [51], based on the idea that all individuals of a society should have the same opportunities to develop their full health potential [51]. However, the current economic crisis in Brazil has led to a cut in funding in many areas, including healthcare, preventing the government from reaching its UHC goal [52].

There are an estimate of 16 million people with disabilities in Brazil [53]. The Brazilian Law of Inclusion states that it is a fundamental right for people with disabilities to have access to high quality healthcare through an interdisciplinary team, adequate infrastructure, appropriate communication resources and necessary assistive devices [54].

The Brazilian Law of Inclusion [54] underscores the importance of addressing barriers through accessibility, universal design, and assistive technology. It centres on principles of non-discrimination, ensuring equal opportunities, reporting violations, and fostering collective responsibility. The law also highlights the obligation of public authorities to uphold the dignity of people with disabilities, addressing matters such as clinical interventions and consent withdrawal. Additionally, it emphasizes the fundamental right to rehabilitation, incorporating elements like multidisciplinary assessment and coordinated efforts by health and social services. The law ensures comprehensive healthcare through the Unified Health System, encompassing aspects such as participation, ethical standards, and professional training. It further mandates preventive measures, inclusive private health insurance, care away from home, and the provision of a companion during hospitalization. Prohibitions against discrimination, variable charging, and violence underscore the law's dedication to inclusivity and the protection of individuals with disabilities.

There are other important policies in place in Brazil to support the right to inclusion, such as the National Health Policy for Persons with Disabilities (PNSPCD). On their paper on the National Policy for people with disabilities in Brazil, Lyra et al discuss the challenges and context of implementing the National Health Policy for Persons with Disabilities (PNSPCD) in Brazil from 2002 to 2018 [55]. They conclude that there has been a complex trajectory of public policies for people with disabilities in Brazil, particularly in the context of healthcare. They note that the development of these policies has faced challenges and successes over the last 50 years, involving various factors such as the disability movement, technical staff, philanthropic institutions, international organizations, and different governments. The neoliberal offensive on social policies is identified as a major obstacle to the consolidation of the National Health Policy for Persons with Disabilities (PNPCD). The authors also acknowledge advances during the Lula and Dilma governments, including Brazil becoming a signatory to the Convention on the Rights of Persons with Disabilities. However, they point out contradictions and a lack of comprehensive healthcare network implementation [56].

More broadly, studies show that these laws and policies are not yet implemented on the ground in Brazil. A study conducted in São Paulo shows that people with disabilities face difficulties in accessing healthcare services in different levels, due to lack of adequate infrastructure and stigma from healthcare professionals [51]. Another study conducted recently in Brazil on the economic impact of Congenital Zika Syndrome, shows a gap in access to healthcare among people with disabilities in Brazil, as well as a need to further understand the barriers [57]. A scoping review conducted in Brazil shows that users of the service face several obstacles to access health services, including breakdowns in communication between professionals and patients/caregivers, financial constraints, attitudinal/behavioural challenges, limited service availability, and organizational and transportation barriers. On the other hand, service providers identified key barriers such as inadequate training for professionals, deficiencies in the health system, physical obstacles, insufficient resources/technology, and language barriers [58]. A similar trend among people with disabilities is seen globally, due to barriers such as stigma and lack of appropriate infrastructure which reduce the capacity to access health services [26, 56, 59-61].

1.3 Participatory research with people with disabilities

There is a clear need for more evidence on the barriers and challenges people with disabilities experience in accessing health, so that services can be improved and the right to healthcare realised. However, people with disabilities have all too often been excluded from research [62]. The Disability Rights Movement clarifies that it is the right of people living with a disability to be included within such studies, as ‘experts by experience’ in their field. This human rights-based approach strongly asserts that everyone has the ability to partake fully and completely - regardless of any form of impairment [63]. Therefore, people with disabilities must not only be accepted but also valued for their essential contributions made around the globe across every sector [62, 63]. Studies have increasingly emphasized the importance of including people with disabilities in their own research through the help of participatory methodologies [62]. The generation of scientific evidence on disability relies on research, which, in accordance with Article 3, Clause 3 of the UNCRPD, must guarantee the "full and effective participation and inclusion of disabled people." This is consistent with the Disability Rights Movement principle of "Nothing about us, without us," which underscores the necessity of meaningful inclusion of disabled individuals in activities that concern them [63]. The significance of participatory approaches in achieving ethical, equitable, and high-quality research practices is well-established [64]. These methods entail shifting power from the researcher to the individuals participating in the research.

Several noteworthy examples of good practices in disability research exist. Co-production has been employed in the development of mental health services and research, aiming to bridge the "relevance gap" in academic research and ensure that findings align with policies and practices [65]. Certain research techniques facilitate participation, such as photovoice, which enables disabled individuals to express themselves effectively and highlight the key impacts on their lives [62, 66]. Arguably, qualitative methods lend themselves most obviously to participation, as there can be participation as an interviewee, interviewer or research designer. Qualitative research often focuses on in-depth interviews, and most recently visual methods have been used to promote more active collaboration [67].

1.3.1 Participatory Visual Methods

Participatory visual methodology involves research participants creating visual material as an integral part of the research process. The use of visual methods in research can be traced back to anthropology, where anthropologists have frequently employed visual media to convey intangible aspects of culture in their research [68]. Visuals have the capacity to bring out emotions and information that are hard to capture during verbal interviews [69]. Images have the power, as written by Susan Sontag, to ‘haunt’ audiences, or as Olins describes to ‘touch’ us [70]. Videos capture informal ways of knowing, through hearing and seeing [41] and audio-visual literacy is universal [71]. Participatory visual methodologies therefore not only contribute to the collection of empirical evidence, but also create a medium that can go beyond a report and publications; it can be disseminated through screenings and exhibitions, reaching various audiences, including communities, policy makers and healthcare professionals [70].

Another advantage is that PV methods provides a mode of inquiry, representation and production that involves the participants actively [70]. This holds particular significance within marginalized communities, enabling them to apply their own discoveries according to local needs [72]. Visuals can also provide entryways to otherwise inaccessible locations and broadens the range of settings in which information can be gathered [41], including capturing non-verbal interactions. Another key aspect of participatory visual research is that it generates participant-generated data, empowering the individuals involved [70]. This fosters a collaborative relationship between the researcher and participant, where they operate as colleagues, bringing distinct skills into a process of mutual learning [73]. Participatory visual methodologies have the potential to reshape the topics under discussion, facilitating learning for both participants and researchers [73-76].

Participatory visual methodologies align with the principles of Paulo Freire - a Brazilian educator and philosopher - [77] emphasizing a broader perspective and comprehension of health and its social determinants. This approach advocates for the promotion of dialogue. There should be a recognition of informal knowledge and meaningful social involvement [71]. Additionally, professionals may have a limited understanding of how lay people experience and understand the health system and its practices. Therefore, capturing data from the perspective of participants is crucial to generating change [73]. As outlined in the WHO Toolkit on social participation, advocating for social participation holds significance in achieving a fair balance of power [78]. For example, Caroline Wang proposes photo novellas as a means to empower participants who possess an in-depth understanding of their communities. This approach allows them to identify and address their own issues, aiming at individual change and enhancing the overall quality of life within the community. She also argues that the use of participatory visual methodologies enables community members to communicate directly to policymakers and has been used to inform policy [79]. This leads to what Freire calls 'concientização' (*conscientisation)*, which enables participants to become aware of their own capabilities in improving their circumstances [77]. Just as Freire developed word lists for literacy classes from the life experiences of his students, to avoid any vocabulary which was not part of their life experience, a photo novella does the same but with photos and descriptions of the photos, where participants portray their own life and community [79].

A literature review of participatory visual methods shows that the most common methods used in research are photovoice, participatory video, drawing, mapping and digital storytelling [70]. All these methods combine a visual aspect as well as an interview or focus group discussion, to capture both the audio-visual or visual and expression of meaning of the participants involved [41]. The most common method is photovoice (initially named photo novella) which was pioneered by Caroline Wang when implementing the process with women in rural China [79]. According to Wang, photo novellas (photovoice) have three main goals, which can be expanded to represent underlying goals of all participatory visual methodologies: To empower the participants to record and reflect on their lives; to enhance the collective knowledge on a specific topic; and to inform the broader society and policymakers of a specific issue [80].

As still images, photos have less of a capacity to capture the complexity of settings than videos do. That is why authors have described video as being an effective tool for capturing interactions among various individuals, including patients, physicians, and other medical and non-medical staff. It also serves to document the interaction between people, technology, and their environment [81]. This is one of the reasons why video was selected as the medium for the participatory visual component of this PhD research. Additionally, I chose video over photos to ensure inclusivity for participants with visual impairments and potentially for people who use sign language. By incorporating audio, video content becomes accessible to a broader audience, including those who may rely more heavily on auditory cues. If subtitled, can be available to hard of hearing or deafened people. This decision aligns with the principles of universal design, aiming to make information available to everyone regardless of their abilities [82]. Furthermore, the audio component of videos adds depth and richness to the content, providing additional context, emotional cues, and enhancing the overall viewing experience. In research, capturing both visual and auditory elements allows for a more comprehensive understanding of the subject matter and facilitates nuanced analysis [83]. Thus, the choice of video not only promotes inclusivity but also enriches the research by leveraging the multisensory nature of the medium.

The heterogeneity of people with disabilities and caregivers, and the complex nature of access suggests the need for a method that can adapt to individual needs and particularities in accessing healthcare people may experience, in a Latin American context. Therefore, as one of the objectives of this study (objective three) I set out to explore the use of two different participatory visual methods that use video – Participatory Video or Digital Storytelling for my study.

1.3.2 Disability and Participatory Visual Methods

Using photography as a research method has become more common among social scientists involving people with disabilities in studies [84-87]. However, video is still a method which is not widely used, and few studies have been identified that use video as a research method with people with disabilities. A systematic review conducted on access to HIV services among individuals with disabilities in Africa [88] identified eight papers addressing the theme, and none of them employed participatory methods, nor visual methods. The predominant methods observed were in-depth interviews and focus group discussions, with participant observation following closely. A study conducted in a separate systematic review by Goli Hashemi focused on qualitative papers addressing primary healthcare access for individuals with disabilities in low and middle-income countries [29]. Hashemi et al. found only one instance, out of 41 papers, that utilized photovoice specifically with children with disabilities in Indonesia [89]. However, this paper does not provide a comprehensive reflection on the simultaneous use of both methods—in-depth interview and photovoice.

A few examples were identified of studies describing the development of participatory videos with people with disabilities. Sitter [90] and Bezzina [91] are two examples of these. The authors delve into the realm of participatory video analysis in disability research, shedding light on both its benefits and challenges. Sitter emphasizes the understudied nature of participatory video analysis, underscoring hurdles related to participant involvement, especially during the editing stage. Balancing choices, time constraints, and unintentional dominance of voices pose significant challenges. The paper advocates for a deeper understanding of how participatory analysis integrates into the overall research methodology, urging further exploration and discourse to address these challenges. On the other hand, Bezzina focuses on the potential for skill development and personal growth through participatory methods. While noting the positive experiences reported by participants, Bezzina acknowledges critiques surrounding participatory video, including concerns about power dynamics, homogeneous assumptions, and potential exclusion of certain disabilities. Reflexivity is highlighted, with Bezzina recognizing the limitations of being a non-disabled researcher from the West and emphasizing the importance of ethical considerations in navigating potential inhibitors in the research process.

Together, these perspectives paint a comprehensive picture of the multi-faceted nature of participatory video analysis in disability research. They underscore the potential power of participatory video in empowering community members to become co-filmmakers, fostering collaboration, creativity, and inclusivity. Simultaneously, they call attention to the intricate challenges involved, urging a nuanced understanding and ongoing dialogue to refine this methodological approach for a more inclusive and effective disability research framework.

There is a need for an increased application of participatory visual methods in engaging people with disabilities, fostering a comprehensive understanding of how to effectively address obstacles while leveraging positive aspects.

1.4 Conclusion

My research underscores the imperative for a more nuanced understanding of barriers to healthcare access for individuals with disabilities, particularly in low- and middle-income countries. Recognizing this need, my PhD journey was meticulously structured to comprehensively address the gaps in qualitative information on these barriers. The systematic review initially delved into available qualitative data on health access barriers, evaluating existing approaches to data collection. Subsequently, employing in-depth interviews provided insights into the core barriers experienced by people with disabilities. The exploration then advanced into different methodologies, with the testing of participatory visual methods as an approach to unravel healthcare challenges. This approach was complemented by further using Participatory Video to get insights into healthcare challenges from a different perspective, as well as to better explore the use of this tool. Ultimately, this research not only contributes to a deeper understanding of healthcare barriers but also sheds light on effective qualitative data collection methods in this crucial domain.

Chapter Two: Methodology

This study involved a systematic review, in-depth interviews, exploration of participatory visual methods, and a participatory video process to support the understanding of healthcare access.

2.1 Study aim and objectives

The study aim was to understand healthcare access in Brazil from both a broad and zoomed in perspective, involving people with disabilities, as well as exploring more accessible ways to engage people with disabilities in research. The aim will achieve this through these objectives:

1. Systematically review the literature to understand barriers and facilitators to primary healthcare access among adults with disabilities in Latin America and the Caribbean (Chapter 3, Paper One)
2. Investigate barriers and facilitators to primary healthcare access among adults with disabilities in Brazil, using in-depth interviews (Chapter 4, Paper Two)
3. Explore the feasibility of using participatory visual methodologies in disability research (Chapter 5, Paper Three)
4. Explore the use of Participatory Video as a method in health research involving people with disabilities (Chapter 6, Paper Four)

2.2 Conceptual framework

2.2.1 Access to healthcare

The concept of healthcare access is intricate. Levesque et al. [92] propose a conceptualisation of healthcare access that delves into "broad dimensions and determinants, integrating demand and supply-side factors, and facilitating the operationalisation of access to healthcare throughout the entire process of seeking and benefiting from services" [92]. Barriers may manifest at various stages in the healthcare-seeking journey. Five dimensions of accessibility have been outlined: Approachability, acceptability, availability and accommodation, affordability, and appropriateness. Correspondingly, five abilities for individuals to interact with services have been identified: Ability to perceive, ability to seek, ability to reach, ability to pay, and ability to engage. This framework will guide my PhD research. I chose this framework because it provides a structure for how to consider the different barriers people with disabilities face - both from demand and supply side across the journey.

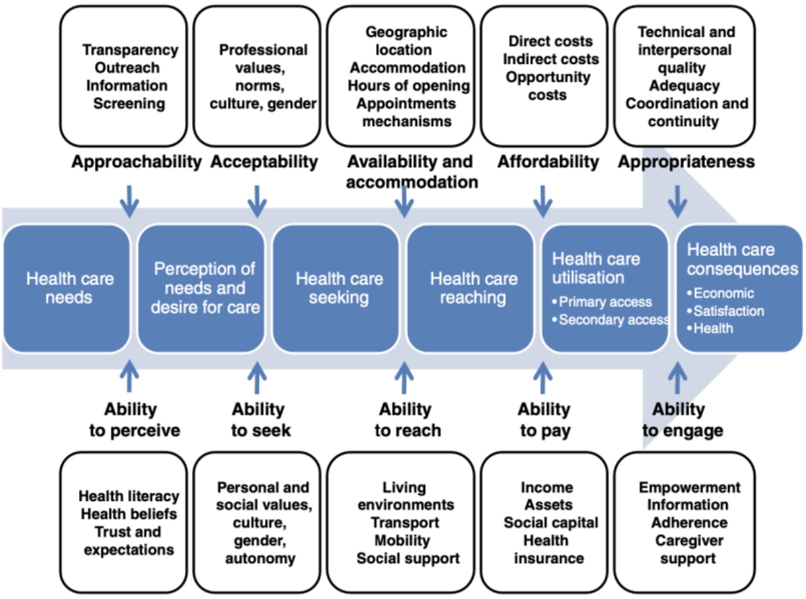

Figure 2: *Levesque's conceptualization of healthcare access [92]*

As a highly diverse demographic, individuals with disabilities confront a range of barriers shaped by factors like impairment type, age, gender, and setting. However, research spanning various countries and encompassing individuals with different impairments has identified common hurdles in healthcare access for people with disabilities. These include challenges related to affordability, physical accessibility, insufficient communication methods, professional skill gaps, and negative attitudes.

2.2.2 Participatory research

Efforts in research, policies, and interventions seeking to be inclusive of individuals with disabilities should actively engage them to guarantee that the outcomes genuinely meet their needs, as outlined in the previous chapter.

In this thesis, the imperative for comprehensive participation is explicitly emphasized, as highlighted in Article 3, Clause 3 of the UNCRPD, which stipulates that research on disability should guarantee the 'full and effective participation and inclusion of disabled people' [11]. The essence of complete participation is intrinsic to human rights principles. The aim is to actively engage individuals with disabilities as partners in the research process, ensuring their voices are not only heard but also actively contribute to shaping the study.

Different conceptualisations of participation have been proposed [93]. One such framework is the "ladder of participation," which was first developed for citizen participation [94], and can be a useful framework to understand people’s participation in research, including studies that encompass individuals with disabilities [95]. At the lowest rung of this ladder lies non-participation or manipulation, where individuals are compelled to take part merely to access a service. Moving up, nominal participation, often referred to as "tokenism," involves simply informing or consulting people with disabilities, this may involve including them in meetings once the research plan is already formulated. Progressing further, partnership or active participation emerges, with disabled individuals actively engaged in designing research, collecting data, and voicing their perspectives. Finally, at the highest level, we find effective participation, characterized by delegated authority or "citizen's control," where the focal group, in this instance, individuals with disabilities, takes charge of most aspects of the research, including financial decisions, or even exercises complete authority. This highest level can also be termed "co-produced" research if it entails collaboration with disabled individuals [96] or "emancipatory" research when disabled individuals assume full ownership of the entire process [97].

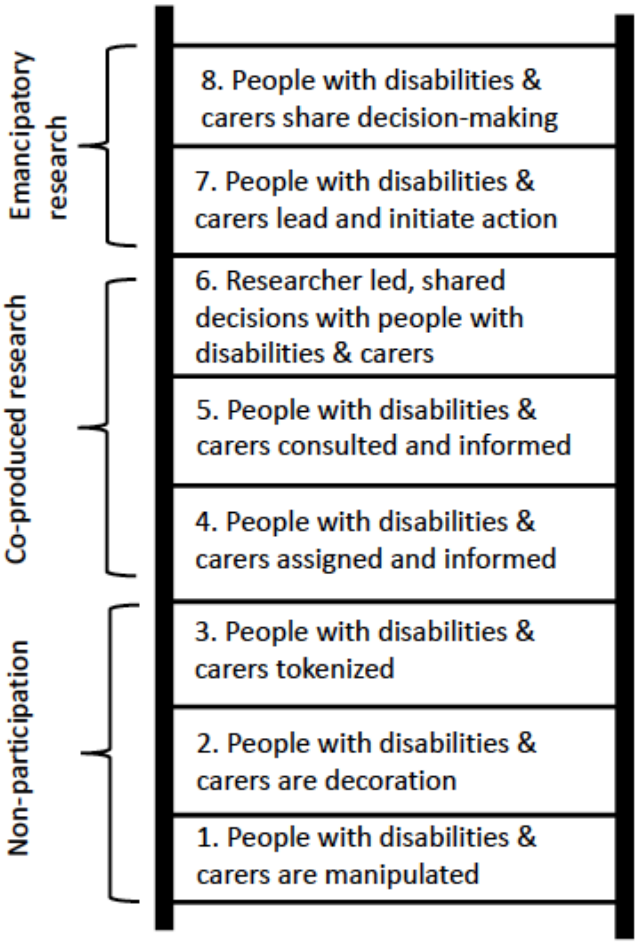

Figure 3: *Ladder of participation for people with disabilities and carers [98]*

The full methods are given in the individual papers. A summarised version is given here for each objective:

2.3 Methods to meet objective 1: Systematically review the literature to understand barriers and facilitators to primary healthcare access among adults with disabilities in Latin America and the Caribbean (Chapter 3, Paper One)

2.3.1 Data collection

The authors collaborated with the International Centre for Evidence in Disability (ICED) and The London School of Hygiene & Tropical Medicine (LSHTM) librarians to develop search terms focused on disability, healthcare and Latin America and the Caribbean. The search, conducted in June 2022, retrieved peer-reviewed articles from six databases—CINAHL, LILACS, MEDLINE, GLOBAL HEALTH, EMBASE CLASSIC, and EMBASE. The literature sought papers published from 2000 onwards, using keywords related to access/barriers to healthcare services, Latin America and the Caribbean, and adults with disabilities. MeSH terms or equivalent headings were employed in the search. Screening involved two researchers independently evaluating titles, abstracts, and full texts for eligibility, with disagreements resolved by a third author. Included studies, published in English, Spanish, Portuguese, French, or Dutch, focused on access to general or primary care services for adults with disabilities in Latin America and the Caribbean, using qualitative data collection methods and constituting original primary research. For additional details, refer to the paper itself.

2.3.2 Analysis

The meta-synthesis adhered to the ENTREQ and PRISMA [99, 100] guidelines, ensuring transparency and systematic reporting of qualitative research synthesis. I conducted data extraction and coding, with subsequent review by two other researchers, Ana Paula Corona and Mansi Baxi. Information under the "results/findings" headings was electronically extracted and input into NVivo 12. Line-by-line coding was employed to identify concepts related to the Levesque framework [92].

2.4. Methods to meet objective 2: Investigate barriers and facilitators to primary healthcare access among adults with disabilities in Brazil, using in-depth interviews (Chapter 4, Paper Two)

2.4.1 Participant selection

Participants with disabilities were identified initially through healthcare centres, followed by the application of snowball sampling. Additionally, we reached out to some Organizations of Persons with Disabilities (OPDs). Eligibility criteria for participation included being above 18 years old and self-reporting 'a lot of difficulty' or 'cannot do' in one or more of the Washington Group Questions [101]. We contacted all participants through telephone calls or email. Our goal was to ensure a balanced representation, encompassing participants with various self-reported disabilities (visual, hearing, intellectual, physical impairment), both men and women, and those older or younger than 65 years old.

2.4.2 Data collection

I, along with local researchers, conducted in-depth interviews. All researchers were selected based on their expertise in public health or psychology and their familiarity with the local context. Notably, two interviewers have disabilities themselves. The in-depth interviews took place between March 2020 and November 2021, coinciding with the COVID-19 pandemic. As a result, all interviews in São Paulo, Santos, and Brasilia were conducted remotely through virtual or telephone calls. The choice of platform was based on each participant's preference and access availability. In Arcoverde, interviews were a mix of remote and in-person sessions conducted when most restrictions were lifted. Participants and interviewers had to be symptom-free and wear masks during face-to-face interviews. While most participants were directly interviewed, carers and family members were involved in cases where individuals had very significant difficulties in communicating or understanding.

2.4.3 Analysis

The researchers familiarized themselves with the data, which entailed revisiting transcripts and field notes to gain a comprehensive understanding of the material. Following this, a first-level thematic analysis was undertaken, categorizing participants' accounts into overarching themes that corresponded the Levesque framework [92]. This initial analysis served to structure the data and gauge the extent to which sub-factors were discussed within the study population.

Subsequently, these broad themes were further deconstructed into sub-themes, sometimes more specific to disability. The relationships between these sub-themes were compared and scrutinized, employing analytical memos within the excel for an in-depth exploration of the data.

For a more comprehensive discussion of this analytical process, please refer to Chapter 4, specifically Paper two, where this methodology is elaborated upon in greater detail. For the Participatory Video process, Chapter 6, paper 4 details the process. Interviews were transcribed for analysis. Codes were created deductively and inductively within a framework approach to map people with disabilities’ healthcare access experience. We used the patient-oriented dimensions of the Levesque framework [92]. To report this study, we used the Consolidated criteria for Reporting Qualitative research (COREQ) [100] to support us in the different stages.

2.4.4 Ethical considerations

Participants with different disabilities took part in the study and it was important to guarantee that all participants were providing informed consent, including those who may have struggled to understand the consent form. The first thing to acknowledge is that people with intellectual disabilities may struggle to give informed consent, as they may not have a complete understanding the requests made of them [102]. To overcome these challenges, the caregiver - an individual, whether paid or unpaid, who provides significant support to individuals with disabilities [103] – was present during the consent process. Caregivers were also an important support for communication, as they may have a better understanding of what participants want to express, as well as provide comfort if they feel uncomfortable in a new environment [104]. Additionally, simplified versions of the consent forms were developed to support direct consent from participants with intellectual disabilities.

The research was approved by the Ethics Committees of all partner institutions. Participants gave informed consent before taking part in the study. Two consent forms were created, a more complex one and a simpler one, to support understanding. Proxy consent was given for people who found understanding the consent form challenging.

2.5 Methods to meet objective 3: Explore the feasibility of using participatory visual methodologies in disability research (Chapter 5, Paper Three)

2.5.1 Participant selection and data collection

Participatory Video

The Participatory Video (PV) process took place in Cali, Colombia, in September 2019, with the objective of exploring the impact of the Juntos program on the lives of caregivers. A group of 11 Colombian caregivers, connected through a WhatsApp group formed during their participation in the Juntos program, was approached to join the PV. One of the Juntos facilitators, present in the WhatsApp group, informed them about the PV, and eight out of the 11 caregivers agreed to participate.

A one-day workshop was conducted by me in a local NGO office. I had the support from Luisa Consuelo Rubiano Perea, from Fundación Casa GAMI, to organise the session. The eight caregivers, consisting of six mothers, one grandmother, and one sister of children with Congenital Zika Syndrome (CZS), attended the workshop with the children. The PV process involved a story circle, where participants shared their experiences with the Juntos program and its impact on their lives. On the same day, they received training on filming. With one camera available, each caregiver took turns filming another, capturing moments like singing to their child. They learned basic camera operations such as starting and stopping, zooming, and checking sound. After practicing, they collectively decided on the content for the final video through storyboarding, with some caregivers talking on camera while others filmed or visually demonstrated activities learned through Juntos (e.g., feeding, playing, creating props).

All caregivers contributed to the decision-making process. Editing discussions took place, and I edited the film based on their suggestions. The final version was agreed upon through dialogues between the facilitator and the caregivers, considering preferences for music, texts, and effects. The completed film was then uploaded and shared with the caregivers for their unrestricted use.

Digital storytelling

The Digital Storytelling (DST) project, following the Story Center methodology [105], was conducted online in September 2020, with the facilitator having undergone training in this approach. Six out of the eight mothers who participated in the PV process engaged in an initial online story circle through the Zoom platform. In this session, conducted as part of the DST project, the mothers explored the experiences of healthcare access for children with disabilities in Colombia, discussing both facilitators and barriers.

During the story circle, participants shared their child's healthcare access journey and selected a specific story they wanted to create a video about. Examples of digital stories were shown to help them visualize how to portray their stories effectively. A week later, another online session took place where caregivers read their stories and provided feedback to each other. Subsequently, caregivers gathered photos and videos to illustrate their stories, which were then submitted to me. The editing process was carried out by me, closely aligning with the participants' suggestions. The finalized videos were shared among the caregivers, with four out of the initial six completing their digital stories, and three having available videos to share.

Semi-structured in-depth interviews and researcher observation notes

In total, four comprehensive semi-structured interviews were conducted with participants who engaged in both the DST and PV methods. The questions covered various aspects of the processes, seeking participants' perspectives on the experience and their thoughts on the outcomes. Topics included empowerment and the effectiveness of conveying their messages. Conducted in Spanish by me, a fluent Spanish speaker, the interviews took place via Zoom, each lasting approximately 45 minutes to one hour. Transcriptions were verbatim in Spanish to preserve the nuances of the participants' responses and were returned to them for content verification before analysis.

2.5.2 Analysis

My observation notes, capturing participant involvement, reactions, and conversations during the process, were also integrated into the analysis. Manual coding of transcripts and observation notes followed an iterative process, identifying central themes as they emerged, and refining and expanding them through the coding process. I actively participated in all three phases of the study, bringing prior training in participatory video, digital storytelling, and qualitative research expertise to the project.

2.5.3 Ethical considerations

Before initiating the interviews, participants received comprehensive information about the study, had any queries addressed, and provided written ethical consent. Additionally, at the conclusion of both the PV and DST processes, an additional oral ethical consent was obtained. During this phase, participants informed the researchers whether they consented to the sharing or usage of the videos.

Full ethical review and approval was granted by the LSHTM Ethics Committee and the Ethics approval for the study was granted by the London School of Hygiene & Tropical Medicine (LSHTM) (No 15986 /RR/ 11098) and Comité de Ética e Investigación Asistencia Cientifica de Alta Complejidad (CEIACAC) Bogota (No CEI-022-19).

2.6 Methods to meet objective 4: Explore the use of Participatory Video as a method in health research involving people with disabilities (Chapter 6, Paper Four)

2.6.1 Participant selection and data collection

The study recruited eleven participants from a larger pool of individuals with disabilities and their carers who initially took part in the interviews for objective two. The selection process for those who were interested involved creating a purposive sample to ensure diversity in age, disability type, and gender among participants. As the time for the participatory work neared, those who had shown interest were re-contacted to confirm their continued willingness to participate and to provide further details about the project. To ensure no one was excluded due to financial constraints or transportation barriers, participants were informed that financial support for transportation and food would be available, and accessible transportation was provided as needed.

The workshop and filming activities spanned four days. The workshop included story circles, learning how to use videos and video-making.

2.6.2 Ethics

The consent process in this study, which received ethical approval from committees in the UK and Brazil, emphasized informed consent throughout. Participants first signed an initial consent form upon agreeing to participate, which detailed the study's purpose, procedures, and potential risks or benefits. After creating the video, a second consent form was signed, addressing privacy concerns and offering options like pseudonyms or face blurring, after participants reviewed the final product and discussed any concerns or requested edits.

2.7 Research collaborators

I am dedicated to the process of fostering cross-cultural learning between regions worldwide to address poverty and reduce inequalities. This commitment is evident in the partnerships and methodologies that have been developed and implemented in the contest of my doctoral research. I collaborated with researchers from the University of São Paulo, University of Pernambuco, and FIOCRUZ. Each research team shared a common dedication to co-production with researchers with disabilities, each hiring researchers with disabilities within their team for the in-depth interview and analysis. As well as providing them a space to build their careers in research, producing first author papers. The data collection team included Gislene Inoue Vieira, Simone Vieira da Silva, Karina Aparecida Padilha Clemente Maria Eduarda Carvalho, Maria Clara Melo, Fábio de Sousa, Willians Melo, Matheus Frazão, Gabriella Morais, Araújo Morais, Ana Carolina Digues da Costa, Soniery Almeida Maciel, Joselia de Souza Trindade and Luisa Consuelo Rubiano Perea. Each member either had prior experience in collecting qualitative data or underwent training to do so. The training included how to conduct interviews with people with different impairments, collecting informed consent and data storage and management.

2.8 Researcher reflexivity

Engaging in a study on healthcare access for adults with disabilities in Brazil necessitates a critical reflection on my own background, experiences, and the complexities inherent in my role as a researcher. As a white European-Brazilian, my identity brings forth a dynamic interplay of cultural perspectives, shaping both my approach to research and interactions with participants. Despite my heritage from my mother’s side being originally from São Paulo, my residence in Brazil has been limited to four years, underscoring the importance of acknowledging the gaps in my extensive understanding of the country's diverse socio-cultural landscapes.

With a background in Visual Anthropology and over eight years of experience as an ethnographic filmmaker, I have come to appreciate the profound advantages of incorporating visual tools in research, particularly when working with diverse populations. It is essential to recognize that while this study is not explicitly ethnographic, my professional history in Visual Anthropology has undeniably shaped my approach. Throughout my career, a commitment to constant self-reflection has been paramount, emphasizing that the substance of the research always takes precedence over the aesthetic aspects of filmmaking. This awareness has been instrumental in navigating the delicate balance between the visual representation and the substantive content of the study. My academic background in Visual Anthropology influenced my methodological choices, leading to the utilization of in-depth interviews and a Participatory Video approach. Notably, the Participatory Video was conducted in Pernambuco state, an area with which I am less familiar. This introduces an aspect of reflexivity, recognizing that my relative unfamiliarity with Pernambuco may influence the interpretation of data and the depth of contextual understanding.

It is crucial to recognize and grapple with the inherent power dynamics as a non-disabled researcher investigating healthcare access for and with individuals with disabilities. My personal connection to the subject matter, sparked by the experience of my brother’s son, Oliver, being born with cerebral palsy and subsequent passing, adds a layer of emotional sensitivity to my engagement with the topic. While I have conducted some studies with people with disabilities in the past, I humbly acknowledge that I consider myself to have limited experience in this domain. The support and guidance received from the International Centre for Evidence in Disability (ICED) over the past five years have been instrumental in fostering my knowledge and expertise in disability research.

Fluency in Portuguese facilitates communication and rapport-building, yet it is essential to recognize that language proficiency does not automatically grant an exhaustive understanding of the intricate nuances within the Brazilian healthcare system, especially in economically disadvantaged areas like Arcoverde (Pernambuco), where the Participatory Video was produced. Embracing these reflections underscores the importance of continuous self-awareness, humility, and openness to learning throughout the research journey, ensuring an ethical and reflexive approach that respects the diverse experiences and voices of those involved in the study.

Chapter Three, Paper One: Access to primary healthcare services for adults with disabilities in Latin America and the Caribbean; a review and meta-synthesis of qualitative studies

Preamble

The decision to undertake a systematic review on healthcare access for adults with disabilities in Latin America and the Caribbean was motivated by the need to comprehensively understand and analyse the prevailing barriers and facilitators in this area. My primary objective was to gain insights into the local context of healthcare accessibility within this expansive region. Latin America and the Caribbean exhibit considerable diversity in terms of healthcare infrastructure, policy frameworks, and socio-cultural factors. By systematically reviewing the available literature, we aimed to identify common themes, gaps, and disparities in healthcare access for adults with disabilities across different countries within this region. This comprehensive understanding is crucial for informing targeted interventions, policies, and initiatives that can address the specific needs of individuals with disabilities in diverse local contexts.

Furthermore, the review sought to explore the range of studies and qualitative approaches used to explore the theme of healthcare access for adults with disabilities in Latin America and the Caribbean. By mapping out the existing research landscape, we aimed to identify gaps in knowledge and areas where further investigation is warranted. This process not only contributes to academic scholarship but also provides a foundation for evidence-based policymaking and interventions. In essence, the systematic review served as a vital step towards creating a holistic understanding of healthcare access for adults with disabilities in Latin America and the Caribbean, paving the way for more targeted and effective strategies to enhance inclusivity and equity in healthcare across the region.

Understanding the regional context is pivotal as it provides valuable insights that directly inform the next step of the study: a more in-depth examination of the Brazilian healthcare landscape. The systematic review supports in equipping me with a comprehensive understanding of prevalent issues and enabling a more nuanced exploration of healthcare challenges and facilitators faced by adults with disabilities in Latin America and the Caribbean.

This strategic approach ensures that my research is attuned to the specific needs and intricacies of the Brazilian healthcare system, thereby enhancing the relevance and applicability of our findings for the benefit of individuals with disabilities in the region.

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SECTION A – Student Details

Student ID Number	1703886	**Title**	Mrs
First Name(s)	Veronika		
Surname/Family Name	Reichenberger		
Thesis Title	Using in-depth interviews and participatory visual methodologies to investigate healthcare access among adults with disabilities in Brazil.		
Primary Supervisor	Loveday Penn-Kekana		

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 Rehabilitation		
When was the work published?	March 2024		
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SECTION E

Student Signature	[redacted]
Date	10/03/2024

Supervisor Signature	[redacted]
Date	10/03/2024

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REVIEW

Access to primary healthcare services for adults with disabilities in Latin America and the Caribbean: a review and meta-synthesis of qualitative studies

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ABSTRACT

Purpose: This review and meta-synthesis of qualitative studies aims to provide an overview of qualitative evidence on primary healthcare access of people with disability in Latin America and the Caribbean, as well as to identify barriers that exist in this region.

Methods: Six databases were searched for studies from 2000 to 2022. 34 qualitative studies were identified.

Results: Barriers exist on both demand and supply sides. The thematic synthesis process generated three broad overarching analytical themes, which authors have related to Levesque et al.'s aspects of "ability to perceive," "availability, accommodation and ability to reach" and "appropriateness and ability to engage." Access to information and health literacy are compromised due to a lack of tailored health education materials. Barriers in the urban environment, including inadequate transportation, and insufficient healthcare facility accessibility create challenges for people with disabilities to reach healthcare facilities independently. Attitudinal barriers contribute to suboptimal care experiences.

Conclusion: People with disabilities face several barriers in accessing healthcare. Lack of healthcare provider training, inappropriate urban infrastructure, lack of accessible transport and inaccessibility in healthcare centers are barriers that need to be addressed. With these actions, people with disabilities will be closer to having their rights met.

IMPLICATIONS FOR REHABILITATION

- The identification of barriers on both the supply and demand sides highlights implications for individuals with disabilities seeking access to primary healthcare services, primarily in Brazil, with similar concerns noted in Colombia and Trinidad and Tobago.
- Service providers should enhance access to people with disabilities by providing accessible information and reasonable accommodation for people with disabilities.
- More training of healthcare professionals is required to support the provision of care for people with disabilities.
- There is a need to improve healthcare centre accessibility, as well as local infrastructure and transportation to prevent people with disabilities from having their rights violated.
- Linkages should be strengthened between sectors like transportation, urban development, and health to enhance overall accessibility and prevent violations of the rights of individuals with disabilities.

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Disability; people with disabilities; primary healthcare; barriers to healthcare; Latin America and the Caribbean; meta-synthesis

Introduction

Disability cannot be regarded as simply a health issue, but if persons with disabilities do not have access to appropriate health services, they cannot enjoy their other rights. The World Health Organization estimated that 1.3 billion people lived with some form of disability in the world in 2021. In Latin America and the Caribbean (LAC), different estimates show that the regional population living with some type of disability is between 66 and 85 million, or 12–15% of the total population [1,2]. Evidence shows that on average, people with disabilities experience worse health status and outcomes than others in the population [3]. This inequity is due to exclusion and marginalization, as people with disabilities are excluded from opportunities such as education and employment [4], which can lead to worse mental and physical health [5,6]. They are also on average older and poorer and experience underlying health conditions often associated with poverty, which also contribute to worse health status. Despite their greater need for healthcare, people with disabilities face greater barriers to accessing healthcare [7–10] and consequently poorer access to healthcare [3]. Key barriers to accessing healthcare are often considered to be approachability (e.g., available information),

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acceptability (e.g., stigma, negative attitudes), availability (accessibility, transport), affordability (lack of insurance coverage), and appropriateness (e.g., poor skills of healthcare providers) [11].

Latin America and the Caribbean is a profoundly unequal and inequitable region, and there are crosscutting social and economic challenges that affect the access of all vulnerable populations to essential services, including healthcare [12]. While more than 218 million people are excluded from social security systems and 140 million people lack access to health services for financial, geographical or cultural reasons, people living with a disability may face additional specific barriers that are unique to their impairment [13].

Countries in the region are working to implement the progressive legal and institutional changes needed to comply with the United Nations Convention on the Rights for Persons with Disabilities [14] and regional frameworks such as the Inter-American Convention on the Elimination of all Forms of Discrimination against Persons with Disabilities [15]. To support these and other initiatives in this field, this study aims to provide an overview of the existing qualitative evidence in relation to the access of people with disability in Latin America and the Caribbean to healthcare, as well as to identify the barriers that exist in this region. Looking at barriers qualitatively will support the understanding of mechanisms and complex networks that may be missed by existing quantitative studies [16–18]. Whilst access is a multidimensional aspect of healthcare, the study adopts the framework proposed by Levesque et al. [19]. This framework uses a comprehensive approach to access by embracing both the characteristics manifested by the systems and service providers and the skills of individuals, families, and communities. The framework proposes five aspects of accessibility from both the provider and user perspectives, examining their interaction. The initial suggested dimension is "approachability" and "ability to perceive," evaluating individuals' capacity to recognize services, the transparency of services, health literacy, and knowledge about health. "Acceptability" and "ability to seek" consider social and cultural factors influencing access, knowledge of healthcare options, personal autonomy, and individual rights. "Availability and accommodation" and "ability to reach" encompass the physical accessibility of healthcare centers, service delivery speed, urban contexts, provider qualifications, and provider availability. On the user side, it considers transportation and mobility. "Affordability" and "ability to pay" relate to the direct costs of services and whether individuals need to pay for them. "Appropriateness" and "ability to engage" assess service quality, ensuring correct treatment and referrals, as well as patients' ability to decide and engage autonomously [19].

Methods

Peer-reviewed articles were retrieved from six databases (CINAHL, LILACS, MEDLINE, GLOBAL HEALTH, EMBASE CLASSIC and EMBASE) by one of the authors (first author) in June 2022. The literature search specifically sought papers published on or after the year 2000, including keywords around the concepts of access/barriers to health care services, Latin America and the Caribbean and adults with disabilities.

We use the definition of disability presented by the The United Nations (UN) Convention on the Rights for Persons with Disabilities: "Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others." [14] Search strings used MeSH terms or equivalent headings (Appendix, supplementary material). At least two researchers consecutively screened titles, abstracts and full texts of each article initially identified for eligibility. Each of the papers were double-screened, and the third author resolved any disagreement.

Included studies were i) published in English, Spanish, Portuguese, French or Dutch (the five main official languages spoken in LAC) on or after the year 2000, ii) conducted in Latin America and the Caribbean countries, as defined by the Pan American Health Organization (PAHO), iii) investigating access to general or primary care services of adults with disabilities (including studies that investigated other age groups, but reported results for the adults separately), iv) used at least one qualitative data collection method (such as focus groups, interviews, or observations), and v) original primary research.

It excluded studies i) conducted outside of Latin America and the Caribbean, ii) investigating rehabilitation services or referral-based services (such as mental health services and other specialized care), iii) that only used quantitative data collection methods, iv) included other age groups and did not clearly differentiate the findings between them, v) commentaries, opinion pieces, letters to the editor, or conference proceedings, economic analyses, systematic reviews, project reports, policy analysis and non-peer-reviewed articles.

All selected papers were assessed for quality by two authors (first and second authors) using the consolidated criteria for reporting qualitative research (COREQ) checklist [20]. To ensure that no crucial elements are omitted, the COREQ checklist provides an extensive view of what should be incorporated into qualitative studies. This ranges from the research team, study design, data analysis and reporting [20]. No paper was excluded, however, based on quality.

The meta-synthesis was performed taking into consideration both the ENTREQ (Enhancing Transparency in Reporting the Synthesis of Qualitative Research), and the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analysis) [21,22]. The data extraction and coding were done by the first author of this paper and reviewed by two other researchers, including the second author of this paper. All text under the headings "results/findings" were extracted electronically and entered into *NVivo 12*. Line-by-line coding was done to find the concepts related to the Levesque framework [19].

Results

The search in June 2022 identified 18,107 papers, of which 2838 duplicates were removed. 15,269 papers were double screened for titles and abstracts, with a third reviewer to resolve any disagreement. Of these, 15,166 were excluded for not meeting the eligibility criteria. One hundred and three articles full texts were reviewed, of which 69 were excluded for not meeting the eligibility criteria, including for not being peer-reviewed, being duplicates, and not being available in full. The details of the screening process involved in identifying the articles in this review are presented in Figure 1.

Of the 34 papers included, 31 were studies conducted in Brazil, two in Colombia, and one in Trinidad and Tobago. Qualitative methods used in the studies were predominantly interviews (28 studies), followed by focus groups (four studies), ethnography (one study), observation (one study) and diary (one study). Twenty-five studies included the perspective of people with disabilities, while the other nine only included non-disabled stakeholders, caregivers and/or healthcare professionals (Table 1). Ten studies focussed on access to healthcare for people with disabilities as a group, while the remaining studies focussed on specific impairment types, including 13 studies looking at people with hearing impairment, five on physical impairment, three on intellectual impairment, and three on visual impairment. The COREQ checklist analysis revealed differences in reporting

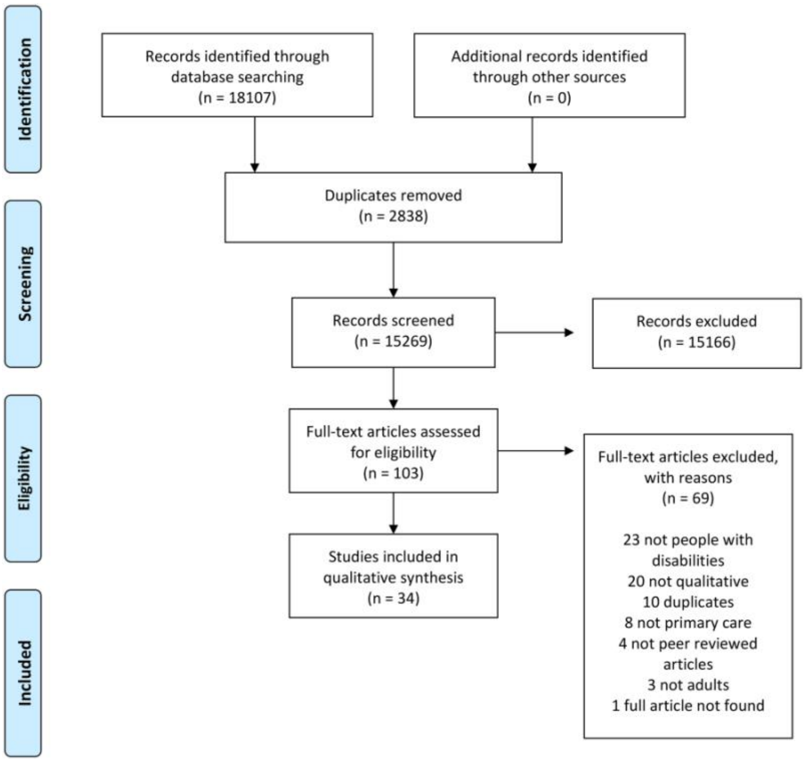

Figure 1. PRISMA flow chart of study identification.

quality amongst the 34 research papers. None of the studies met all the requirements on the checklist. Most of the studies reported on theoretical framework, derivation of themes, data, clarity of major themes and presented quotes (Table 2).

Codes and analytical themes

The thematic synthesis process generated three broad overarching analytical themes, which authors have related to Levesque et al.'s aspects of "ability to perceive," "availability, accommodation and ability to reach" and "appropriateness and ability to engage."

Ability to perceive

Perceiving healthcare needs refers to access to information on health and health literacy. Most health education materials target people without visual or hearing impairments, which leaves out many people with disabilities. This review revealed that lack of accessible healthcare information and health education campaigns and opportunities affected mostly participants who have a visual impairment or a hearing impairment [37,40,43,46,50,52]. Six studies show the importance of receiving information and having accessible information on healthcare issues and how information is mostly available in text form, through posters, billboards and pamphlets, making them inaccessible to people with visual impairment [37,40,43,46,50,52]. Gaps in accessible information were found regarding sexual health, cancer prevention and oral hygiene.

For example, in one of the studies, a healthcare centre coordinator in Brazil described how the centre does not provide all the material they have in accessible forms:

> We don't have personalized material, for example, for the visually impaired, we don't have video with [Brazilian sign language] Libras, we don't have material in Braille and they don't have access to information in a clear way like the general population. [43]

Lack of accessible information can enhance the vulnerability of people with disabilities [46]. Participants who could not find information from healthcare sources, such as doctors or their healthcare practice, reported seeking information from peers, primarily those with a similar impairment as their own, in the same age group, or people they know. One study reveals that people who are hearing impaired found information on sexually transmitted diseases primarily through friends and neighbours because of a lack of access to information [52]. The lack of educational

Table 1. Description of eligible studies.

	Study	Region, Country	Perspective	# of participants	# of participants with a disability	Type of Impairment	Data collection strategy
1	Tedesco et al. [53]	Porto Alegre/RS, Brazil	Healthcare professionals	13	0	Hearing	Interviews
2	De Miranda et al. [44]	Rio de Janeiro/RJ, Brazil	Persons with disabilities	24	24	Hearing	Focus group discussions
3	Oliveira et al. [35]	João Pessoa/PB, Brazil	Persons with disabilities	11	11	Hearing	Interviews
4	Chaveiro et al. [29]	Goiânia/GO, Brazil	Persons with disabilities	20	20	Hearing	Interviews
5	Fernandes et al. [57]	Vitória da Conquista/BA, Brazil	Healthcare professionals	70	0	Not specified	Focus group discussions
6	Castellanos Soriano et al. [58]	Bogotá, Colombia	Community leaders, elderly people of the neighbourhood, family and elderly people with disabilities	31	7	Physical	Participant observation and interviews
7	Ribeiro de Lago et al. [59]	Mato Grosso, Brazil	Persons with disabilities, family and healthcare professionals	5	1	Physical	Interviews
8	Lenardt et al. [49]	Curitiba/PR, Brazil	Caregivers	14	0	Cognitive	Interviews
9	de Oliveira et al. [60]	João Pessoa/PB, Brazil	Persons with disabilities	11	11	Hearing	Interviews
10	Gomes et al. [34]	Joao Pessoa/PB, Brazil	Persons with disabilities	24	24	Visual	Interviews
11	Ianni et al. [30]	São Paulo/SP, Brazil	Persons with disabilities, caregivers, stakeholders	25	2	Hearing	Interviews
12	Santos et al. [42]	Rio de Janeiro/RJ, Brazil	Persons with disabilities	6	6	Physical	Interviews
13	Fontanella et al. [40]	São Carlos/SP, Brazil	Healthcare professionals	16	0	Cognitive	Interviews
14	Pereira et al. [50]	Natal/RN, Brazil	Persons with disabilities	30	30	Hearing	Interviews
15	Cruz et al. [38]	Campina Grande/PB, Brazil	Persons with disabilities	16	16	Visual	Questionnaires with open questions
16	Mattevi et al. [56]	Porto Alegre/RS, Brazil	Persons with disabilities and caregivers	23	15	Physical, cognitive, visual, multiple	Focus group discussions
17	Fiorati et al. [23]	Ribeirão Preto/SP, Brazil	Persons with disabilities	10	10	Physical, cognitive, multiple	Interviews
18	Nicolau et al. [51]	São Paulo/SP, Brazil	Persons with disabilities	15	15	Physical, visual, hearing, cognitive	Interviews
19	Costa et al. [46]	Minas Gerais/MG, Brazil	Persons with disabilities	9	9	Hearing	Interviews
20	Bentes et al. [52]	Crato/CE, Brazil	Persons with disabilities	12	12	Hearing	Interviews
21	Santos Sales et al. [26]	Bahia/BA, Brazil	Healthcare professionals, social workers	9	0	Not specified	Interviews
22	Aokia et al. [55]	São Paulo/SP, Brazil	Persons with disabilities	5	5	Physical, cognitive and multiple	Interviews
23	França et al. [24]	Paraiba, Brazil	Healthcare professionals	20	0	Spinal cord injury	Interviews
24	Carvalho et al. [28]	Natal/RN, Brazil	Persons with disabilities	12	12	Physical	Interviews
25	Miranda et al. [25]	Rio Grande do Norte, Brazil	Healthcare professionals	12	0	Cognitive	Interviews
26	Othero et al. [45]	São Paulo/SP, Brazil	Healthcare professionals	6	0	Not specified	Interviews
27	Dubow et al. [54]	Rio Grande do Sul, Brazil	Healthcare professionals and stakeholders	49	0	Not specified	Interviews
28	Monteiro et al. [48]	Rio Grande do Norte, Brazil	Persons with disabilities	30	30	Visual	Interviews
29	Gil Cano et al. [37]	Medellin, Colombia	Persons with disabilities	12	12	Hearing	Focus group discussions and questionnaires
30	Fernandes et al. [41]	Fortaleza/CE, Brazil	Persons with disabilities and teachers	40	20	Hearing	Participant observations and questionnaire
31	Castro et al. [47]	São Paulo/SP, Brazil	Persons with disabilities	25	25	Physical, visual, hearing	Semi-structured questionnaire
32	Santos et al. [27]	Rio de Janeiro, Brazil	Persons with disabilities	121	121	Hearing	Mixed-methods; interviews
33	Cardoso et al. [43]	Goiânia/GO, Brazil	Persons with disabilities	11	11	Hearing	Interviews
34	Parey et al. [36]	Trinidad, Trinidad and Tobago	Persons with disabilities	26	26	Physical, cognitive, sensory, multiple	Interviews

Table 2. Comprehensiveness of reporting using the COREQ checklist.

No	Item	No of studies ($n = 34$)	Research studies
Domain 1: Research team and reflexivity			
Personal Characteristics			
1	Interviewer/facilitator	7	[6–12]
2	Credentials	15	[7–9,12–23]
3	Occupation	10	[6–9,11,12,14,15,24,25]
4	Gender	23	[6–14,16,17,19,20–29,34]
5	Experience and training	8	[8,9,10,13,15,21,27,34]
Relationship with Participants			
6	Relationship established	1	[9]
7	Participant knowledge of the interviewer	1	[9]
8	Interviewer characteristics	7	[8,9,10,15,21,27,34]
Domain 2: study design			
Theoretical framework			
9	Methodological orientation and Theory	31	[1–3,6–32,34]
Participant selection			
10	Sampling	28	[1–12,14,16–18,20–22,24–29,31,32,34]
11	Method of approach	14	1,2,3,4,7,8,10,14,17,23,26,27,29,34
12	Sample size	34	[1–34]
13	Non-participation	4	[4,5,27,28]
Setting			
14	Setting of data collection	23	[1–11,13–18,22,23,25–29,34]
15	Presence of non-participants	8	[4,9,11,15,17,18,23,27]
16	Description of sample	26	[2–5,7–17,20–23,25–29,31,34]
Data Collection			
17	Interview guide	24	[1,5,6,9,10,11,13–19,21–25,28–32,34]
18	Repeat interviews	0	
19	Audio/visual recording	21	[2,5,9,10,12,14,15,17–19,21,23,25,26,28–34]
20	Field notes	2	[7,27]
21	Duration	6	[6,10,19,26,27,34]
22	Data saturation	12	[1,2,3,5,12,15,17,21,28,29,31,34]
23	Transcripts returned	3	[7,14,34]
Domain 3: Analysis and findings			
Data analysis			
24	Number of data coders	3	[10,31,34]
25	Description of the coding tree	29	[4–13,14,15,17–34]
26	Derivation of themes	31	[1,2,5–33]
27	Software	4	[3,11,29,25]
28	Participant checking	2	[30,34]
Reporting			
29	Quotations presented	31	[2–30,32,34]
30	Data and findings consistent	33	[1–30,32–34]
31	Clarity of major themes	31	[2–30,32–34]
32	Clarity of minor themes	1	[2]

resources regarding breast cancer in braille or audio recordings made it difficult for blind women to access information about their health. Women in this study revealed not feeling confident with their knowledge of self-breast exams.

Data were lacking exploring this issue for people with intellectual impairments, although they are likely to have faced informational barriers leading to difficulties in perceiving healthcare needs.

Availability, accommodation and ability to reach

Urban environment

Studies show that the urban environment, in particular the surrounding areas of healthcare facilities, also contribute to barriers to accessing services [26,34–36,45,47,51,52,55,56]. Reaching primary healthcare units is not a route people with disabilities report undertaking frequently, so they must be extra careful to avoid objects, uneven pavement, or holes. A visually impaired person in Brazil noted:

> At the front [of the healthcare facility] there are only steps, it's super difficulty, and there are potholes in the street that are sometimes open and that we run the risk of falling into […] I have already fallen twice in front of the local healthcare facility. [34]

The same study shows how the main barriers for people who are visually impaired are running into obstacles in the street, as well as crossing the road alone and having difficulty taking the bus [34]. Participants who are visually or physically impaired mentioned the importance of having someone to help them to reach healthcare centres because of these difficulties with the urban environment, mostly counting on family members to accompany them [34,35,55], which creates additional barriers to accessing care.

Transportation

Difficulties with transportation were revealed as another important barrier to accessing care. Studies show the importance of fare waivers, door-to-door transportation services, and of positive passenger and driver attitudes towards people who have a visual impairment in public transportation, such as the support of the driver who waits for him to enter the bus [56]. On the other hand, attitudes were not always so favourable, and a participant from a study conducted in Trinidad explains:

> Taxi and public transportation drivers don't treat blind persons kindly […] They just stop and would not take the extra minute to drop you in a place where it is convenient so that when you step out of the car you're not stepping into a drain [water channel] or into the middle of the road. [36]

The distance of healthcare centres also affects participants' ability to reach them, as the nearer the centre, the easier it is for participants to go on their own, as revealed by a study conducted in Brazil with hearing-impaired participants [35].

Some healthcare centres provide their own transportation for users, which proves to be especially important, as noted by a psychologist in a family healthcare centre in Bahia, Brazil, who explained the situation of a patient of hers who has an intellectual impairment:

> Today he is no longer in receiving care because we, unfortunately, no longer have the car. The car here at the unit is broken. [26]

The lack of transportation leads to loss of follow-up and care for patients who have no other means to reach services. Additionally, adequate transportation reduces the need for the dependency of someone to accompany users to appointments and check-ups, who sometimes depend on elderly family members to take them to services [55].

Healthcare facility accessibility

When talking about his local healthcare centre, a patient with a visual impairment in Brazil states:

> The entrances are bumpy, there is no handrail, there is nothing to indicate the door, if it had those tactile floors it would be great because we would be able to orient ourselves there, and we would be safe knowing that there would be no obstacles. [34]

Other studies in Brazil revealed similarities:

> There's no ramp in the health service. They've already called me three times, but I can't go, because there's no ramp to get in; and when there is a ramp, there's no handrail. (Physically impaired service user) [47]

> My [patients] are carried by family members! Because, at the entrance door, there is no such access! There's no reason why it's high [the sidewalk]. Then, they usually are carried inside, we receive them in a wheelchair and arrive in my consultation room. And we do what we can do. (Nurse) [57]

People with visual impairments describe the importance of not only reaching the healthcare centre, but also getting around from room to room once they arrive at the facility. This struggle to reach rooms was also expressed by people with a physical impairment, as many facilities did not have ramps or elevators for users to reach other floors.

> We have problems with Pap smears because the gynaecology room is upstairs, there is no staircase. [51]

The above quote illustrates the struggle for women with physical impairment to take necessary tests in healthcare centres that have no ramps or elevators to reach examination rooms. Studies also show the need for accessible stretchers, as the lack of accessible equipment and unsupportive staff means people are unable to undertake important health checks [34,47,51,57].

The review also revealed a lack of healthcare facility accessibility for people with a hearing impairment. A hearing-impaired man in Brazil, mentioned missing their appointments while already in the waiting room because of lack of accessible communication methods:

> As a deaf person it's difficult… I wait and wait, because I do not hear or know where to go. [43]

As illustrated above, the lack of accessible communication methods and appropriate support means, for example, that hearing-impaired patients struggle in the waiting room to know when they have been called. That creates a need for social support, which could be prevented if visual information was provided as well [29,43].

Healthcare professionals showed an awareness of the need for improved accessibility, such as accessible bathrooms, signs, elevators, ramps, and tactile flooring [26,29,30,34,45,47,51,57]. They also mentioned the importance of the availability of wheelchairs for users with mobility impairments [26] and the service being organised to meet the users' needs [45].

Appropriateness and ability to engage

Healthcare provider training

The healthcare providers expressed a general perspective that more training is needed on disability and that providing care for people with disabilities requires special assistance [25,30,40,56]. Healthcare professionals providing care for patients with spinal cord injury say, for example, they have no experience in providing care for this patient group but try to provide the best care they can [24]. Additionally, healthcare professionals described not understanding the specific care needs for people with Down Syndrome or psychosocial impairment and thinking that they will not provide the best care to them, so they prefer to refer them to other healthcare professionals [25,26].

> I confess that we never received any guidance or specific training to serve this type of client, so it would be complicated and difficult to provide this type of service to a person with Down syndrome. [25]

On a similar note, a nurse in Brazil mentions her struggle in providing care to patients with a psychosocial impairment:

> (…) there are a lot of patients with mental disorders and we have this difficulty calling for preventive care. So, many of them are left without doing it, because there are some that are very advanced disorders, which cannot be done! [26]

Some studies in this review reported the importance of training to improve quality of care from the perspective of users as well, who often refer to the lack of preparedness of healthcare professionals and the need for a better knowledge from professionals about people with disabilities.

A participant in a focus group in Brazil recounted a bad experience with an untrained professional:

> (…) when you find some [care], it's not good, because the professional that should be assisting people is not prepared for the [disabled] person. He opens the office door, looks at the person, gets afraid… The appointment lasts 5 minutes and he prescribes the medication without knowing the cost. [56]

This quote shows the lack of preparedness of healthcare professionals and the need for a better knowledge from professionals about people with disabilities.

Interpersonal quality of care

A number of studies reveal attitudinal barriers [25,40,42,51,56], including belittlement and even misdiagnosis because of prejudice, for example, not believing a physically disabled woman was pregnant:

> They did a transvaginal ultrasound and saw the gestational sac, but they said it was my probe balloon. […] They went back to do a new ultrasound. The same doctor who did the other one said that he was wrong, that it was really a child, that maybe he had used his emotion instead of reason because he didn't believe that a quadriplegic could be pregnant. [42]

Stigma was identified in the interviews with healthcare professionals in primary healthcare setting. For instance, studies revealed infantilization of people with Down Syndrome, referring to them as children, even when talking about adults [25,40]. Some participants, for example, blamed the healthcare professional's attitude for not providing health information they sought, such as recounted by a woman with physical impairment:

> When I started dating a boy aged 18–19, and my family found out, they were desperate, then they took me to the doctor and it was a horrible situation, because the gynaecologist put an anatomy book in my face, looked and said, 'Do you see this here, you can't use it!' He said: 'Look, you have everything the same, do you know what the reproductive system is? You have to know that you can't do anything with your body.' Those were the words he used. […] It was a very annoying situation, very painful, because I was thinking that I was going to clarify doubts because I had a lot of questions. He didn't ask for any exam, he didn't even think about my health. [51]

Communication

Along with attitudinal barriers that led to health professionals not dialoguing with people with disabilities about health, this review found an additional barrier for people with a hearing impairment or a visual impairment regarding communication [29,34,35,38,43,44]. There was a fear of being deceived, fear of not understanding what is happening in the consultation because it was not explained in a way that was clear to them, including when communicating important information on therapeutic procedures and treatment plans. Participants mentioned not always feeling comfortable with having family in the consultation with them, although there was no other option. They also needed to find appointments that fit not only their schedule but the family member who was going with them, which added a layer of difficulty. Additionally, participants in the studies in this review revealed that healthcare professionals would many times direct their comments and questions to the family member instead of the individual themselves. As recounted by a hearing-impaired individual:

> I wish that the deaf could go more to health services, taking care of their own health, be able to talk about what they feel about their health that could have a real communication with the professionals in health services, a real care with equality for all. [35]

One study conducted in Brazil with participants who are hearing impaired mentions healthcare professionals are not conducting their work responsibly if they are not communicating important information on therapeutic procedures and treatment plans to their hearing-impaired patients [44]. Some quotes from this paper say:

> We arrive at the hospital and the doctor, nurse speaks, delivers the paper to the table, doesn't even look properly, he has to leave the room. (P4) Sometimes I go for a gynaecological exam and I don't know what I have. Then write in Portuguese and it's easy for me, but I don't understand the name of the medicine. (P6) Professionals talk fast and I don't understand anything. (P15) When he starts talking fast I ask him to speak slowly, I'm deaf, then he says: 'Oh, sorry.' But then he speaks quickly again. (P16) [44]

Unfortunately, no papers were identified that explored this issue for people with intellectual impairments.

Discussion

This is the first meta-analysis of qualitative research on access to primary healthcare for adults with disabilities in Latin America and the Caribbean. The review found evidence that people with disabilities in Latin America experience difficulties in accessing health services. We used the Levesque framework to analyse and report the findings. Our findings show that the "dimensions" and "abilities" identified as barriers were "ability to perceive," "availability and accommodation," "ability to reach," "appropriateness" and "ability to engage" [19]. As the Levesque framework is not a framework used particularly to look at healthcare access for people with disabilities, some interpretations were made by the authors of this paper to fit the framework and support analysis and presentation of findings. Some findings did not fit a analytical theme of its own, such as family and social support, but is present throughout the different findings and is nuanced below. The lack of accessible information was added to "ability to perceive" as without information, people will not be able to have "health literacy" and "knowledge about health." When looking at cultural beliefs about disability and health, Hashemi's systematic review, which included papers from Indonesia, South Africa, among others [39], found that people with disabilities often end up seeking care from traditional healers rather than healthcare services, because of a belief that disability is related or caused by higher powers, such as religion or witchcraft. This pattern is not something that was found in this review. Religion or spiritual beliefs did not appear to get in the way of people's healthcare-seeking attitudes in Latin America.

Consistent with previous reviews, we identified key issues with lack of accessibility of primary healthcare access [39], such as the lack of ramps. This finding is also largely supported by quantitative studies that audited healthcare facilities in the region [17,18]. Lack of accessible transportation and healthcare facility accessibility have been found as barriers in Latin America and have also been highlighted in Hashemi et al.'s review [39]. Our review shows that challenges to reaching services were caused by a lack of appropriate urban infrastructure, and the need to have someone accompanying them to healthcare services, due to the route being an uncertain one with possible obstacles. Family and social support was important when taking transportation and even going around the healthcare centre when the infrastructure was not adequate. Family and social support is a crosscutting issue identified throughout the different analytical themes and plays a key role in people's ability to reach and engage with healthcare services. People with disabilities in our review reported the importance of a positive experience with transportation and how that supports them to go to services. Transportation is necessary because healthcare centres are not close enough to participants' houses. A systematic review undertaken on travel time and its impact on health outcomes revealed that the relationship between worse health outcomes and travel time should be taken into account when discussing healthcare service location, as its location has a potential impact on healthcare outcomes [31].

Our review is consistent with two previous reviews in identifying a general unmet need for healthcare provider training as there was reported lack of knowledge and skills and communication difficulties [32,39]. Our review showed that some healthcare providers even expressed preferring not to provide care for people with certain disabilities because they believe they would not provide the best care for their patients. This creates an extra barrier, as primary healthcare providers are not providing the care patients need and often refer them to specialist services, hindering the continuity of care and stressing the referral pathways for those who actually need it. Patients with disabilities within our review also reported stigma from healthcare providers, misdiagnosing them or treating them disrespectfully.

Affordability was another barrier found in Hashemi et al.'s review which was not found in this review [39]. This is most likely because all countries included in our review have universal healthcare coverage, and although some affordability barriers will have arisen (such as with the indirect costs of transportation), they were not a major theme [33].

There are important programme and research implications of our findings. Service providers should enhance access to people with disabilities by providing accessible information and reasonable accommodation for people with disabilities. More training of healthcare professionals is required to support the provision of care for people with disabilities. There is also a need to improve healthcare centre accessibility, as well as local infrastructure and transportation to prevent people with disabilities from having their rights violated [14]. This would be facilitated with the strengthening of linkages between sectors, such as transportation, urban development and health. There are key research gaps remaining. There is limited evidence about healthcare access for people with intellectual impairments in Latin America and the Caribbean. Additionally, more research is required in different regions of Latin America and the Caribbean, beyond Brazil.

Strengths and limitations of the review

A key strength of the review is that it is the first meta-analysis of qualitative research on access to primary healthcare for adults with disabilities in Latin America and the Caribbean. Moreover, we used gold-standard review methods, including use of multiple databases, dual screening, and quality assessment. Data from this study came from three groups of people: people with disabilities, their caregivers, and healthcare providers. Although most participants were people with disabilities, having information from different perspectives helped minimize gaps in the findings. Studies in multiple languages were eligible (Portuguese, Spanish, English, French, Dutch). The Levesque framework was used as a conceptual framework for the review. The review included 36 papers from a variety of literature sources, allowing us to identify themes and gain insights that would not have been possible through single studies. However, we must still be cautious and limit extrapolation, particularly since most papers are from Brazil. Certain groups were also lacking, such as people with intellectual impairments, meaning we cannot generalize the findings to all people with disabilities. The primary data from each study was inaccessible to us, so we relied on the reports from the authors included in the studies. These reported considerable variability according to their COREQ checklist but tended to be quite low.

Conclusion

This review explored access to primary healthcare services for adults with disabilities in Latin America and The Caribbean. A number of barriers relating to both supply- and demand-side factors were identified for people with disabilities to access primary healthcare services, mostly in Brazil, but also in Colombia and Trinidad and Tobago. Limited qualitative evidence is available on healthcare access for people with disabilities in other Latin American and Caribbean countries, as well as lack of evidence on healthcare access for people with intellectual impairments. This evidence gap is important and must be filled with future research. Lack of healthcare provider training, inappropriate urban infrastructure, lack of accessible transport and inaccessibility in healthcare centres are barriers that have to be addressed for persons with disabilities to receive effective and appropriate healthcare. Persons with disabilities have a right to health under Article 25 of the Convention on the Rights of Persons with Disabilities. If these barriers can be overcome, persons with disabilities will be closer to having their rights met.

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Supporting information [see Appendix 1]

Search Terms

ENTREQ Checklist

PRISMA Checklist

Chapter Four, Paper Two: Access to primary healthcare services: the perspective of adults with disabilities in Brazil

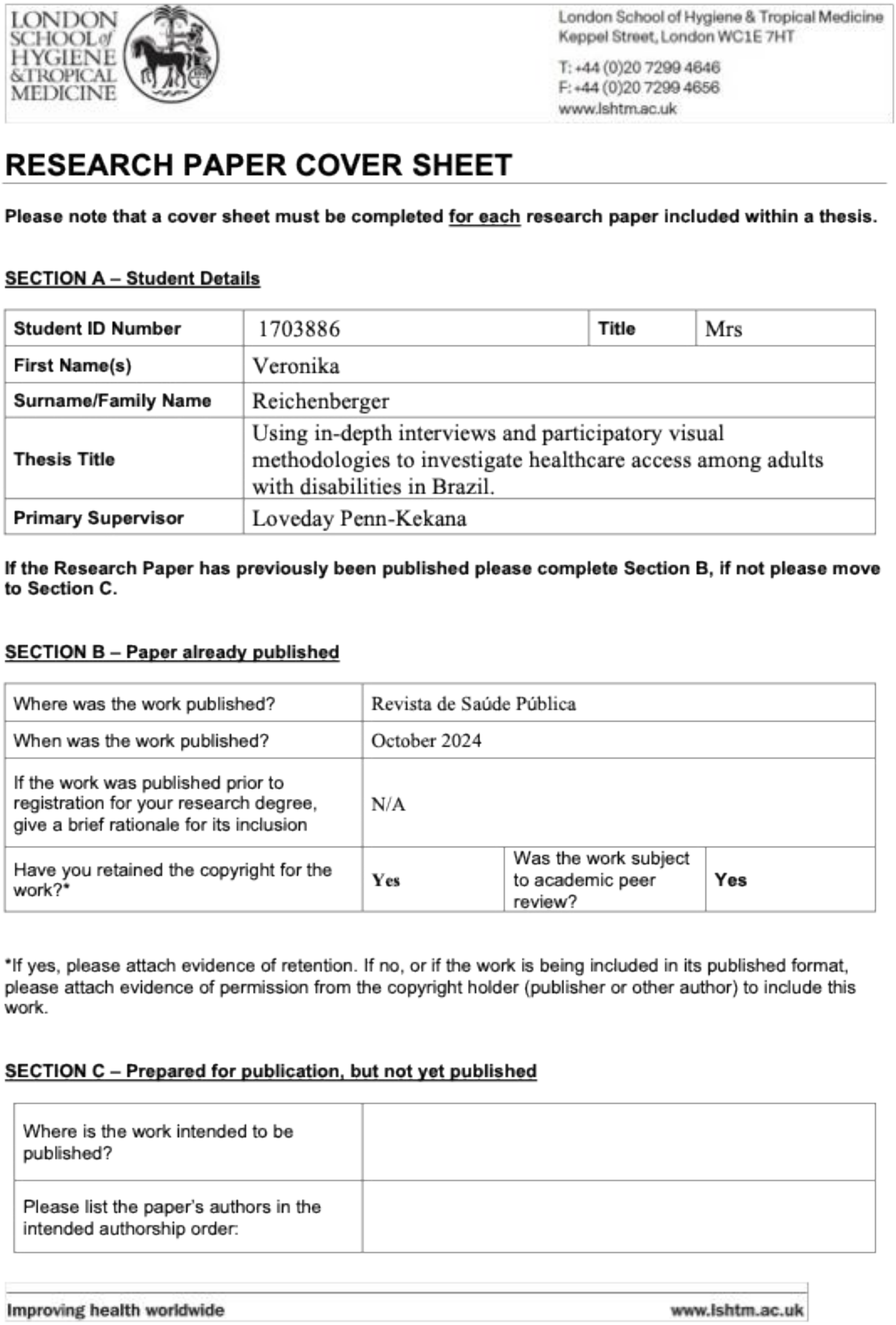
Preamble

The decision to conduct a study on healthcare access for adults with disabilities in Brazil across three distinct states stems from a multifaceted rationale. By concentrating our study within the Brazilian context, we aim to provide a nuanced and comprehensive understanding of healthcare access challenges faced by adults with disabilities within the country. Brazil's vast geographical and socio-economic diversity calls for an exploration that goes beyond a singular regional perspective. By delving into four different cities in three states, pointed out by the stars in the map below, our study endeavours to capture the heterogeneity in healthcare experiences, considering the unique urban, suburban, and rural dynamics prevalent in each region. Moreover, the choice of examining regions with significant disparities in GDP within Brazil amplifies the depth of our investigation [106]. Data was collected in the rural region of Arcoverde (Pernambuco state), the suburban region of Santos (São Paulo state) and the urban regions of Brasília (Distrito Federal) and São Paulo (São Paulo state).

This paper is underpinned by the principles of the International Classification of Functioning, Disability and Health (ICF), which provided a foundational framework guiding the exploration of how various factors influence the healthcare experiences of adults with disabilities in Brazil. While the Levesque framework was specifically utilised to analyse the barriers to healthcare access, the ICF informed the broader understanding of disability, ensuring a holistic consideration of both environmental and personal factors throughout the research.

Figure 4: The flag and map of Brazil with stars pointing to Arcoverde, Brasilia, São Paulo and Santos [107]

The study's focus on Brazil and its diverse states serves to paint a comprehensive picture of healthcare access for adults with disabilities, considering geographical, socio-economic, and urban-rural variations. This holistic approach positions our research to contribute valuable insights to the broader discourse on inclusive healthcare practices within the Brazilian context.



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Primary Supervisor	Loveday Penn-Kekana		

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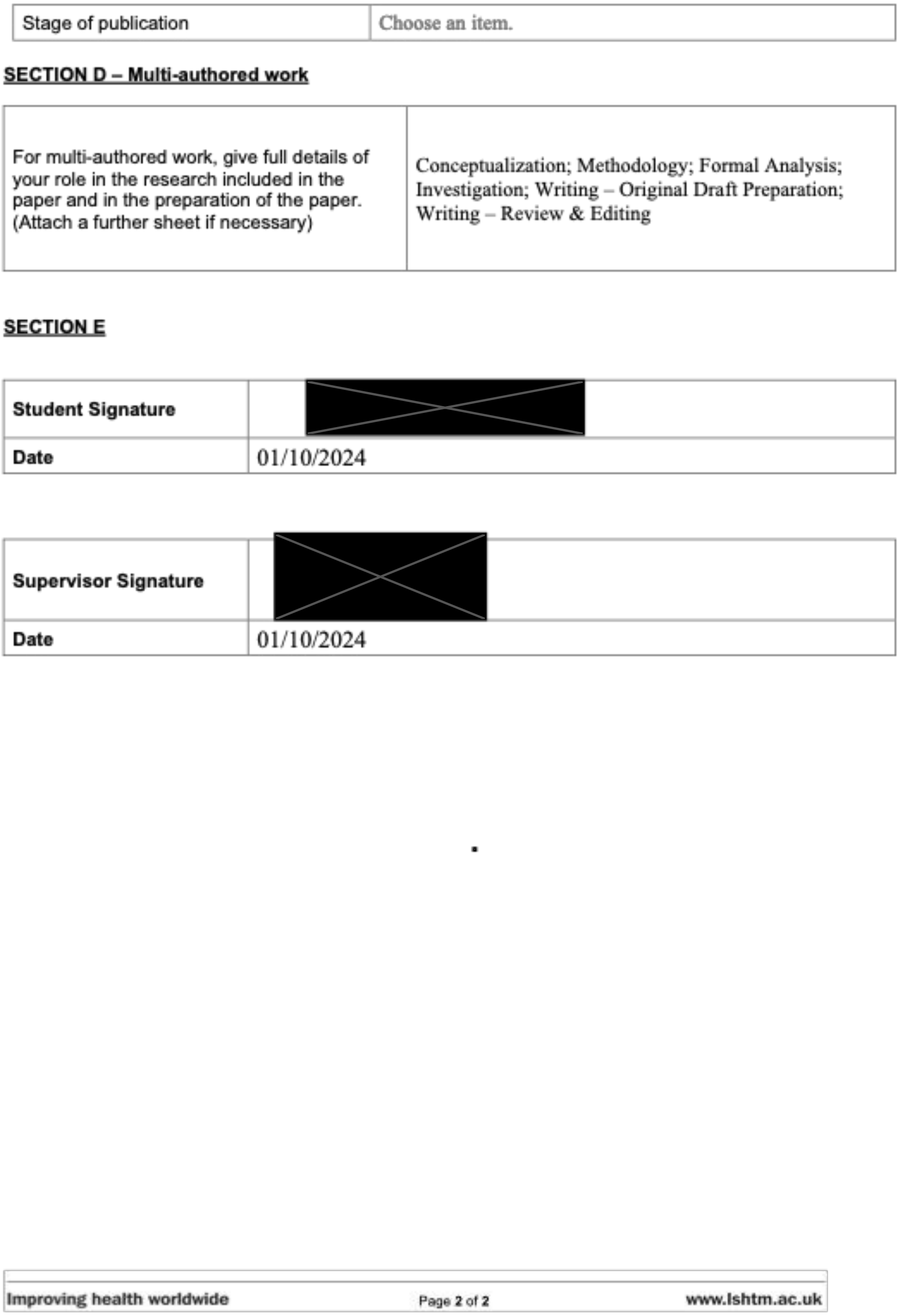

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Access to primary healthcare services among adults with disabilities in Brazil

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ABSTRACT

OBJECTIVE: To investigate perspectives of people with disabilities in Brazil regarding the access to primary healthcare.

METHODS: In-depth interviews were conducted with 44 individuals with disabilities in Pernambuco, Distrito Federal, and São Paulo between March 2020 and November 2021. These interviews were transcribed, coded, and analysed thematically, using the Levesque framework to identify healthcare access barriers.

RESULTS: Participants expressed a solid understanding of their healthcare needs and existing obstacles. However, individuals with hearing and visual impairments experience challenges because of communication barriers. In Pernambuco, the Community Health Agent was often the initial point of contact for primary care services. Public transportation lacked accessibility, from buses to driver attitudes, posing difficulties for people with disabilities. More accessible transportation and improved urban infrastructure could enhance service access. High medication costs were reported due to limited healthcare unit availability. Communication accessibility issues, inadequate audio-visual resources and equipment were also identified as barriers. Attitudinal barriers among healthcare professionals and subpar home visit services further hinder access.

CONCLUSION: To address these challenges and improve the well-being of individuals with disabilities in Brazil, comprehensive action is essential. This includes leadership, governance, and resource allocation reforms to meet healthcare needs. Initiatives like disability-focused training for service providers, enhanced transportation options, improved information accessibility, and increased support from community healthcare workers can collectively enhance the lives of people with disabilities.

DESCRIPTORS: Health Services Accessibility. Health Services for Persons with Disabilities. Barriers to Access of Health Services. Health Information Systems.

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https://doi.org/10.11606/s1518-8787.2024058005842 1

INTRODUCTION

Globally, 1.3 billion people have disabilities[1], with at least 17.3 million living in Brazil, comprising 8.4% of the population[2]. Studies have indicated that individuals with disabilities often have worse general health[1,3], which is partially attributable to existing health conditions and underlying impairments[4]. Furthermore, socioeconomic factors, including age and economic status, contribute to their health disparities[5,6].

Discrimination and barriers to healthcare access exacerbate these challenges. According to Othero and Dalmaso[7], in relation to the health of people with disabilities, access was identified as the main need of this population, seen in a broader way, including access to opportunities, movement in the city, and available services.

Brazil's policy affirms the fundamental right of people with disabilities to high-quality healthcare, emphasizing interdisciplinary teams, suitable infrastructure, communication resources, and assistive devices[8]. The Brazilian Unified Health System (SUS) has played a pivotal role in advancing human rights and diminishing social disparities, notably enhancing access to essential services[9].

Prior to 2011, healthcare for people with disabilities in Brazil was a notably overlooked aspect of SUS. The turning point occurred when the National Plan for the Rights of People with Disabilities, known as the Living Without Limits Plan, was established through Decree 7.612 in November 2011[10]. This strategic initiative is designed to champion the complete realization of the rights of individuals with disabilities by seamlessly integrating and coordinating policies, programs, and actions. Consequently, the nation embarked on a trajectory of meaningful progress, actively working towards providing essential support for this segment of the population.

Against this historical context, the establishment of the Network of Care for the Health of People with Disabilities was a pivotal step. This initiative was designed with the primary goal of fostering and expanding connections among healthcare services and ensuring access that is characterized by quality, equity, and comprehensive healthcare standards[11]. The innovative structure of the new Network encompasses distinct levels of care, including Primary Care, Specialized Rehabilitation Care, and Hospital and Urgent and Emergency Care. Within each level, services serve as focal points for specific actions in the care of people with disabilities. However, seamless access to these services necessitates active coordination between them, emphasizing the importance of a well-integrated healthcare system.

As outlined in Ordinance GM/MS No. 793/2012, the Primary Care component within the organization of the Care Network designates Basic Health Units as pivotal points for care, encompassing NASF-AB and Dental Care[11]. This approach not only contributes to broadening access but also enhances the quality of care for users with disabilities[11]. Leveraging its extensive reach and proximity to communities, primary care, functioning as care coordinator, assumes a crucial role in championing equitable access for users with disabilities. This ensures tailored care that addresses the specificities and vulnerabilities identified in this demographic.

Presently, a significant challenge persists in the form of inadequate coordination between primary care teams and other components within the Care Network for People with Disabilities, hindering the effective implementation of the ordinance. Examining the guidelines and organizational framework of the Health Care Network (RAS), as recommended in Ordinance 4.279/2010, revealed a pronounced and concerning fragmentation among actions and services within the network[12]. This fragmentation not only signifies a vulnerability but is also evident in the care practices for individuals with disabilities. Noteworthy peculiarities emerge, delving into aspects of the work process consolidated within primary care teams, particularly emphasizing NASF-AB and the Home Care

Service (SAD), both crucial support points for the Care Network[13]. Research conducted in São Paulo revealed challenges in healthcare access, which were attributed to deficient infrastructure and healthcare provider stigma[14]. Similarly, children with Congenital Zika Syndrome face significant obstacles, such as stigma and inadequate infrastructure, which hinder their access to vital healthcare services[15].

Previous research on healthcare access for individuals with disabilities in Brazil has frequently been limited in scope, often focusing on single regions[7,14-19]. Consequently, the objective of this study was to investigate the perspectives of people with disabilities in various regions of Brazil, with a specific focus on the barriers to and facilitators of access to primary healthcare services.

We used the Levesque et al. framework (Figure), which supports the conceptualisation of access to healthcare. The framework consists of five dimensions to access from both the supply and demand sides. Thus, we focused on the patient-centric "demand" aspects of the framework.

METHODS

Overview of Study Design and Setting

In-depth interviews were conducted with adults with disabilities and carers in Arcoverde (Pernambuco state), Brasilia (Distrito Federal state), Santos (São Paulo state) and São Paulo (São Paulo state) (March 2020 to November 2021).

Sampling and Recruitment

Participants with disabilities were identified through healthcare centres, and snowball sampling was then applied. Some Organisations of Persons with Disabilities (OPDs) were also contacted. Participants were eligible to take part if they were above 18 years old, who

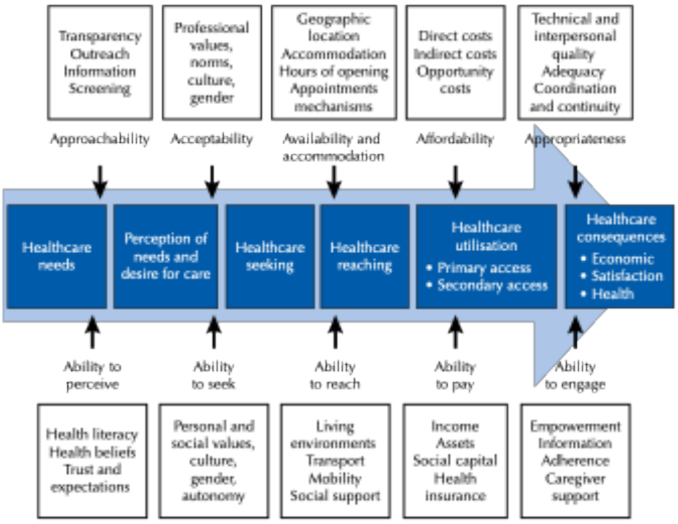

Figure. Levesque et al.[20] framework on healthcare access.

reported having 'a lot of difficulty' or 'cannot do' in one or more of the Washington Group Questions[21]. All participants were approached through telephone or email. We aimed to include a balanced number of participants who self-reported having different disabilities (visual, hearing, intellectual, physical impairment), including men and women, and those older or younger than 65 years.

Data Collection

In-depth Interviews

In-depth interviews were conducted by local researchers, as well as the first author. Although questions about the impact of COVID-19 on healthcare accessibility were posed, they are not aligned with the scope of this paper. The objective of this paper is to comprehend accessibility independent of the pandemic's influences. All researchers were chosen because of their expertise in the field of public health or psychology and their local knowledge. Two interviewers themselves have a disability.

In-depth interviews were conducted between March 2020 and November 2021, which coincided with the COVID-19 pandemic. Consequently, all interviews in São Paulo, Santos, and Brasilia were conducted remotely, through virtual or telephone calls. The platform was chosen according to the preferences and access availability of each participant. Interviews in Arcoverde were conducted when most restrictions were lifted; therefore, there were a mix of remote and in-person interviews. Participants who were interviewed in person as well as interviewers were required to have no COVID-19 symptoms and to wear a mask during the interview. Most participants were interviewed directly, but interviews with caregivers and family members were used for people with severe difficulties in communicating or understanding. The interview guide was created based on the Levesque framework[20] and serves as a tool to facilitate the development of interview guides. It includes open-ended questions to aid in exploring additional themes that may emerge.

Data Analysis

Interviews were transcribed for analysis. Codes were created deductively and inductively within a framework to map the healthcare access experiences of people with disabilities. We used the patient-oriented dimensions of the Levesque framework (Figure). To report this study, we used the Consolidated criteria for Reporting Qualitative research (COREQ) to support us in the different stages[22]. The transcribed interviews were analysed following Bardin[23] and Kvale's[24] hematic cores of meaning approach to unveil deductive categories of access by Levesque et al.[20]. Some inductive categories arose and were kept.

Ethics

The research was approved by the Ethics Committees of all partner institutions. Participants gave informed consent before taking part in the study. Two consent forms, a more complex form and a simpler form, were created to support understanding. Proxy consent was given for those who found understanding the consent form challenging.

RESULTS

A total of 44 participants took part in this study, nine in Arcoverde, 16 in Brasilia, six in Santos, and 13 in São Paulo. Most participants interviewed had a physical impairment (24 participants–while 11 had a visual impairment, 4 had a hearing impairment, and 8 had an intellectual impairment). Of these, three had multiple impairments (Table).

This study employed the access dimensions delineated by Levesque et al.[20], who comprehensively defined access as the opportunity to fulfill health needs, enabling individuals to navigate

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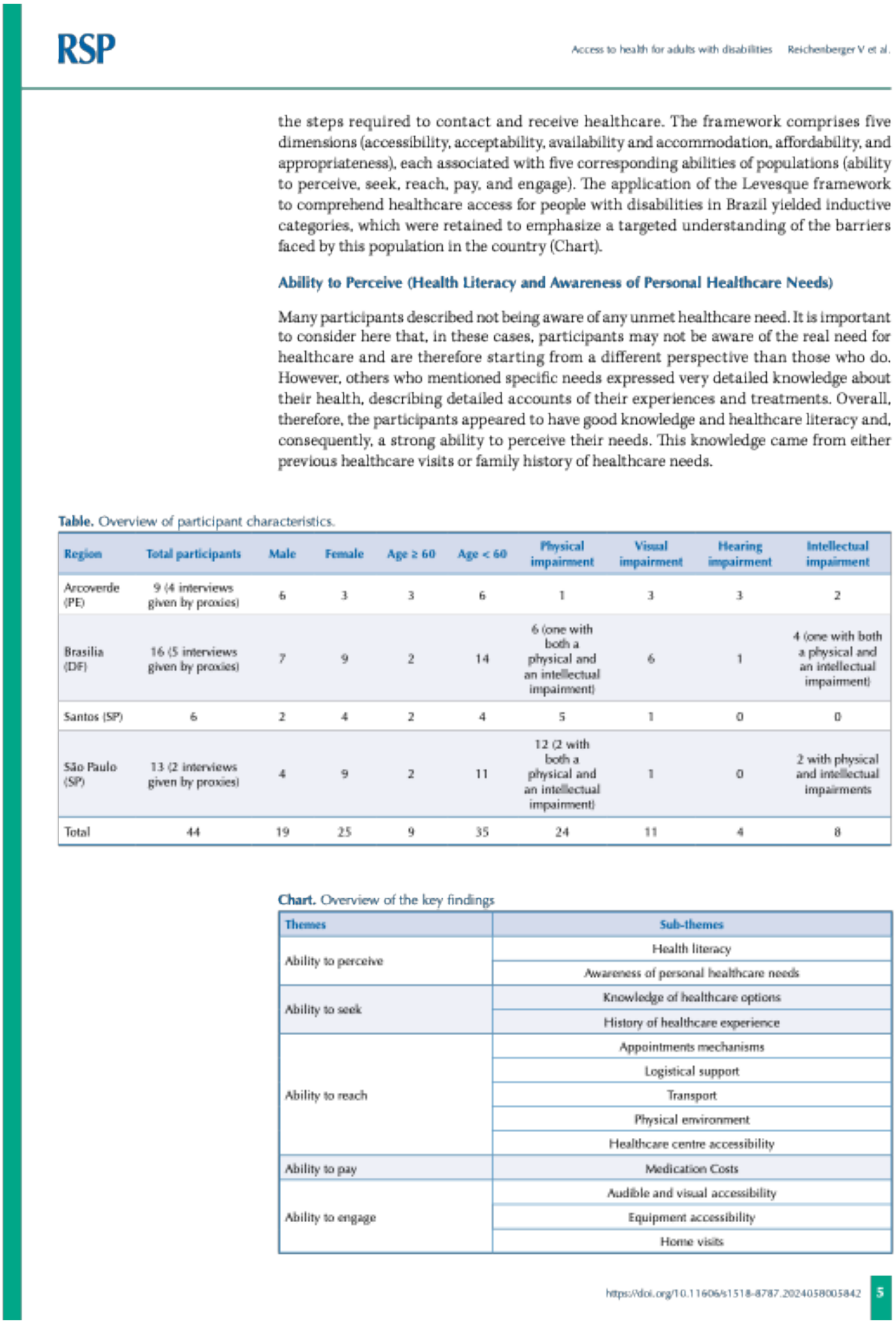


the steps required to contact and receive healthcare. The framework comprises five dimensions (accessibility, acceptability, availability and accommodation, affordability, and appropriateness), each associated with five corresponding abilities of populations (ability to perceive, seek, reach, pay, and engage). The application of the Levesque framework to comprehend healthcare access for people with disabilities in Brazil yielded inductive categories, which were retained to emphasize a targeted understanding of the barriers faced by this population in the country (Chart).

Ability to Perceive (Health Literacy and Awareness of Personal Healthcare Needs)

Many participants described not being aware of any unmet healthcare need. It is important to consider here that, in these cases, participants may not be aware of the real need for healthcare and are therefore starting from a different perspective than those who do. However, others who mentioned specific needs expressed very detailed knowledge about their health, describing detailed accounts of their experiences and treatments. Overall, therefore, the participants appeared to have good knowledge and healthcare literacy and, consequently, a strong ability to perceive their needs. This knowledge came from either previous healthcare visits or family history of healthcare needs.

Table. Overview of participant characteristics.

Region	Total participants	Male	Female	Age ≥ 60	Age < 60	Physical impairment	Visual impairment	Hearing impairment	Intellectual impairment
Arcoverde (PE)	9 (4 interviews given by proxies)	6	3	3	6	1	3	3	2
Brasilia (DF)	16 (5 interviews given by proxies)	7	9	2	14	6 (one with both a physical and an intellectual impairment)	6	1	4 (one with both a physical and an intellectual impairment)
Santos (SP)	6	2	4	2	4	5	1	0	0
São Paulo (SP)	13 (2 interviews given by proxies)	4	9	2	11	12 (2 with both a physical and an intellectual impairment)	1	0	2 with physical and intellectual impairments
Total	44	19	25	9	35	24	11	4	8

Chart. Overview of the key findings

Themes	Sub-themes
Ability to perceive	Health literacy
	Awareness of personal healthcare needs
Ability to seek	Knowledge of healthcare options
	History of healthcare experience
Ability to reach	Appointments mechanisms
	Logistical support
	Transport
	Physical environment
	Healthcare centre accessibility
Ability to pay	Medication Costs
Ability to engage	Audible and visual accessibility
	Equipment accessibility
	Home visits

Some participants had higher healthcare needs and required regular examinations. One participant in Arcoverde (PE) mentioned using a urinary catheter five times a day because he has a neurogenic bladder and intestine.

> *"I have a recurring bladder infection, so I need to be cared for closely, or else I can even risk dying." (Man with physical impairment, 51, PE)*

Participants who had a history of chronic health conditions, such as high blood pressure, depression, and diabetes, also had consistent check-ups and expressed good awareness of the healthcare habits they should adopt. One physically impaired woman in São Paulo reported having check-ups every six months for blood pressure and anemia. Thanks to her check-ups, medical staff were able to identify the onset of thrombosis and treat it before it progressed. Participants frequently reported very good understanding of what led to specific complaints, reporting that doctors were good at explaining their health condition. However, poorer healthcare literacy was mostly reported by hearing impaired participants, visually impaired participants, and intellectually impaired participants, which is reported further under 'Ability to engage', as it is linked to communication barriers.

Ability to Seek (Knowledge of Healthcare Options and History of Healthcare Experience)

Participants reported knowing their primary healthcare options, including where to go and who to seek when this need arises. Some participants, mostly from Pernambuco, reported their "community healthcare agent" (a community health worker) as their first port of call.

The main factor affecting participants' decision not to seek care, however, was past unsatisfactory experiences with healthcare, including negative attitudes, lack of accessibility, and unmet needs. As expressed by one participant:

> *"I prefer to self-medicate because the barriers are so many." (Physically impaired woman, 39, DF)*

More examples of attitudes and physical accessibility are reported under 'Ability to reach' and 'Ability to engage'.

Ability to Reach (Appointment Mechanisms, Logistics Support, Transport, Physical Environment, Healthcare Centre Accessibility)

Appointment mechanisms

While the waiting time to see a healthcare professional is often long, the consultations tend to be short. Participants reported distress due to long waiting times in facilities and how this affects people differently, according to their impairment type. Wheelchair users struggle with waiting in the same position for long hours, as well as the lack of accessible toilets. A mother of a son with Down Syndrome mentioned the struggle for waiting hours in a hospital waiting area, and her son getting uneasy and stressed, so they occasionally leave before seeing a doctor. A woman who became visually impaired in 2009 explains:

> *"It's important for me that I can be seen by a doctor quickly. I don't like to wait long periods of time in crowded places, it bothers me. When I had my sight, it was already distressing, but now it's much worse." (Woman with visual impairment, 43, PE)*

One visually impaired participant reported the lack of an accessible online booking system leading him not to be able to book appointments on his own. Other visually impaired individuals mentioned booking via telephone or needing someone to book appointments on their behalf.

Logistical support

The need for logistical support to reach healthcare services, mostly provided by family members, was reported by all participants with a physical or visual impairment. Family members of participants with intellectual impairment also reported accompanying them to services. This need varied from requiring support in only one specific moment (e.g. putting their wheelchair into a car) or support throughout the entire journey and at the healthcare centre. For participants who are physically impaired, this was reported as one of the first barriers to reach healthcare services.

> *"I used to have a heart condition, and I didn't do the appropriate check-ups because it was hard to find someone to go with me. I need help pushing my wheelchair because I don't have enough arm strength to do it myself." (Man with physical impairment, 61, DF)*

Some participants needed support throughout the whole process, from leaving the house to entering a consultation room. As reported by a man with visual impairment in Santos:

> *"It's not just about arriving at my healthcare centre, when I'm there, it's hard to know what consultation rooms to go to, and there's no braille in the lifts." (Man with visual impairment, 48, SP)*

Transport

The absence of accessible transportation was predominantly noted by individuals with physical or visual impairments. Among participants with visual impairments in all areas, there was a common sentiment of discomfort when considering independent use of public transportation. Instead, they expressed a preference for utilizing private services, which included options like motorcycle taxis in Pernambuco, or relying on apps such as Uber, as reported in both Distrito Federal and the State of São Paulo.

> *"I have my trusted motorcycle taxi driver who takes me where I need to. I have to pay, yes, but at least I know I can trust him, and I feel comfortable. It's also cheaper than taking cars." (Woman with visual impairment, 43, PE)*

> *"My biggest difficulty is this, going out into the street, [...] I always depend on someone, on my husband, my son. And if we need to go anywhere farther away, we always need to pay to go by car using one of those applications." (Woman with visual and physical impairment, 64, DF)*

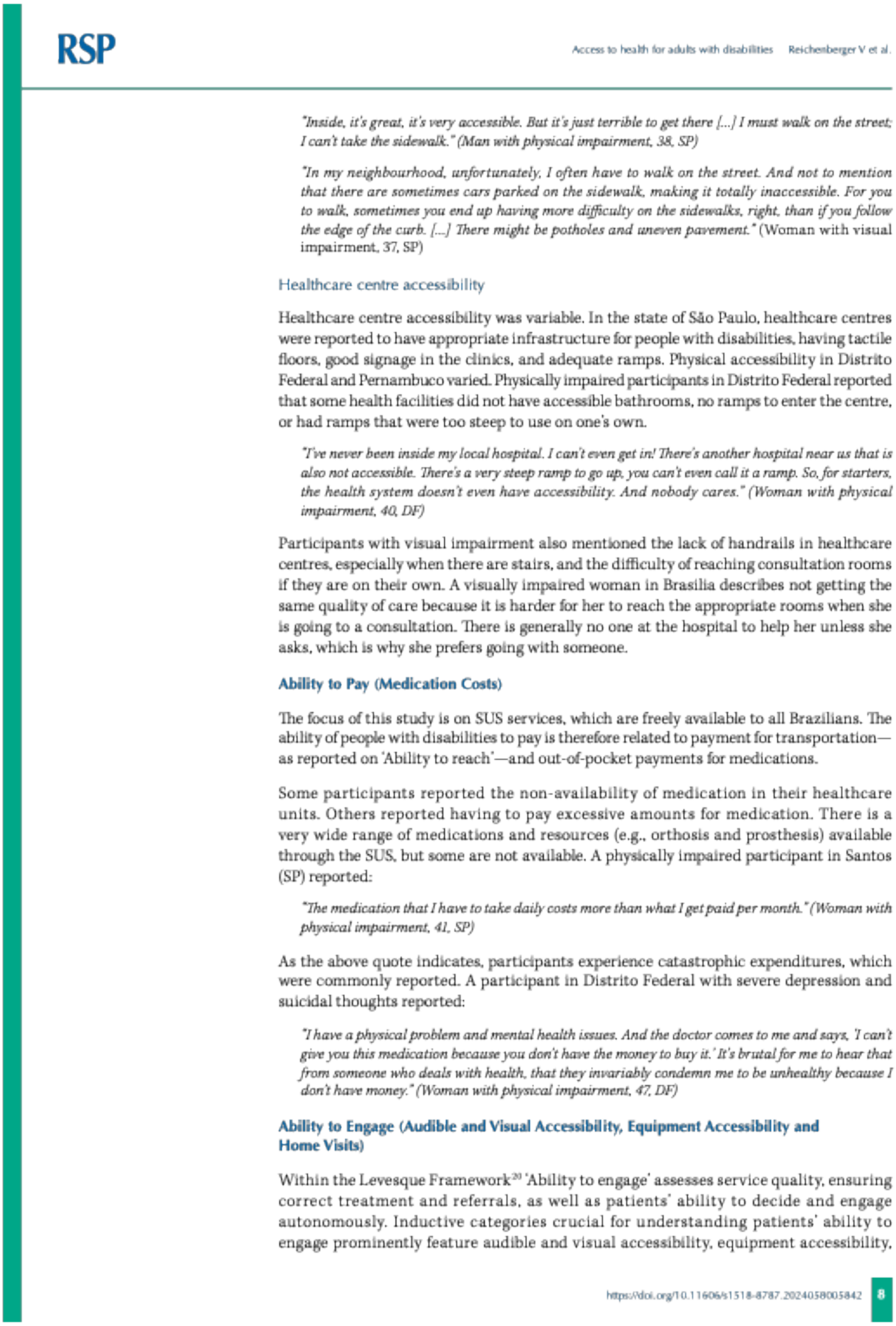
There is a lack of appropriately maintained accessible transportation, and broken ramps prevent users from entering public buses. Additionally, bus drivers sometimes do not stop when they see wheelchair users because *"they consider it a hassle to stop and help us on"* reported a physically impaired man in Distrito Federal. This left participants with no or few free transportation options.

> *"The electric ramp on buses doesn't always work. And while they try to get it down, people look at me angrily. That's why my husband and I walk as far as we possibly can." (Woman with physical impairment, 41, SP)*

Participants in Arcoverde (PE) did not report on the quality of public transportation because it was scarce. Most people travel by motorcycle taxi or shared vans. The exception was the city of São Paulo, which has a public service called 'Atende +' provided by the local government. It is reported to be accessible, easy to book, and very comfortable.

Physical environment

The physical environment or urban infrastructure around the healthcare facility was frequently reported as a barrier to healthcare services, mostly by participants with visual or physical impairments.



> *"Inside, it's great, it's very accessible. But it's just terrible to get there [...] I must walk on the street; I can't take the sidewalk." (Man with physical impairment, 38, SP)*

> *"In my neighbourhood, unfortunately, I often have to walk on the street. And not to mention that there are sometimes cars parked on the sidewalk, making it totally inaccessible. For you to walk, sometimes you end up having more difficulty on the sidewalks, right, than if you follow the edge of the curb. [...] There might be potholes and uneven pavement."* (Woman with visual impairment, 37, SP)

Healthcare centre accessibility

Healthcare centre accessibility was variable. In the state of São Paulo, healthcare centres were reported to have appropriate infrastructure for people with disabilities, having tactile floors, good signage in the clinics, and adequate ramps. Physical accessibility in Distrito Federal and Pernambuco varied. Physically impaired participants in Distrito Federal reported that some health facilities did not have accessible bathrooms, no ramps to enter the centre, or had ramps that were too steep to use on one's own.

> *"I've never been inside my local hospital. I can't even get in! There's another hospital near us that is also not accessible. There's a very steep ramp to go up, you can't even call it a ramp. So, for starters, the health system doesn't even have accessibility. And nobody cares." (Woman with physical impairment, 40, DF)*

Participants with visual impairment also mentioned the lack of handrails in healthcare centres, especially when there are stairs, and the difficulty of reaching consultation rooms if they are on their own. A visually impaired woman in Brasilia describes not getting the same quality of care because it is harder for her to reach the appropriate rooms when she is going to a consultation. There is generally no one at the hospital to help her unless she asks, which is why she prefers going with someone.

Ability to Pay (Medication Costs)

The focus of this study is on SUS services, which are freely available to all Brazilians. The ability of people with disabilities to pay is therefore related to payment for transportation—as reported on 'Ability to reach'—and out-of-pocket payments for medications.

Some participants reported the non-availability of medication in their healthcare units. Others reported having to pay excessive amounts for medication. There is a very wide range of medications and resources (e.g., orthosis and prosthesis) available through the SUS, but some are not available. A physically impaired participant in Santos (SP) reported:

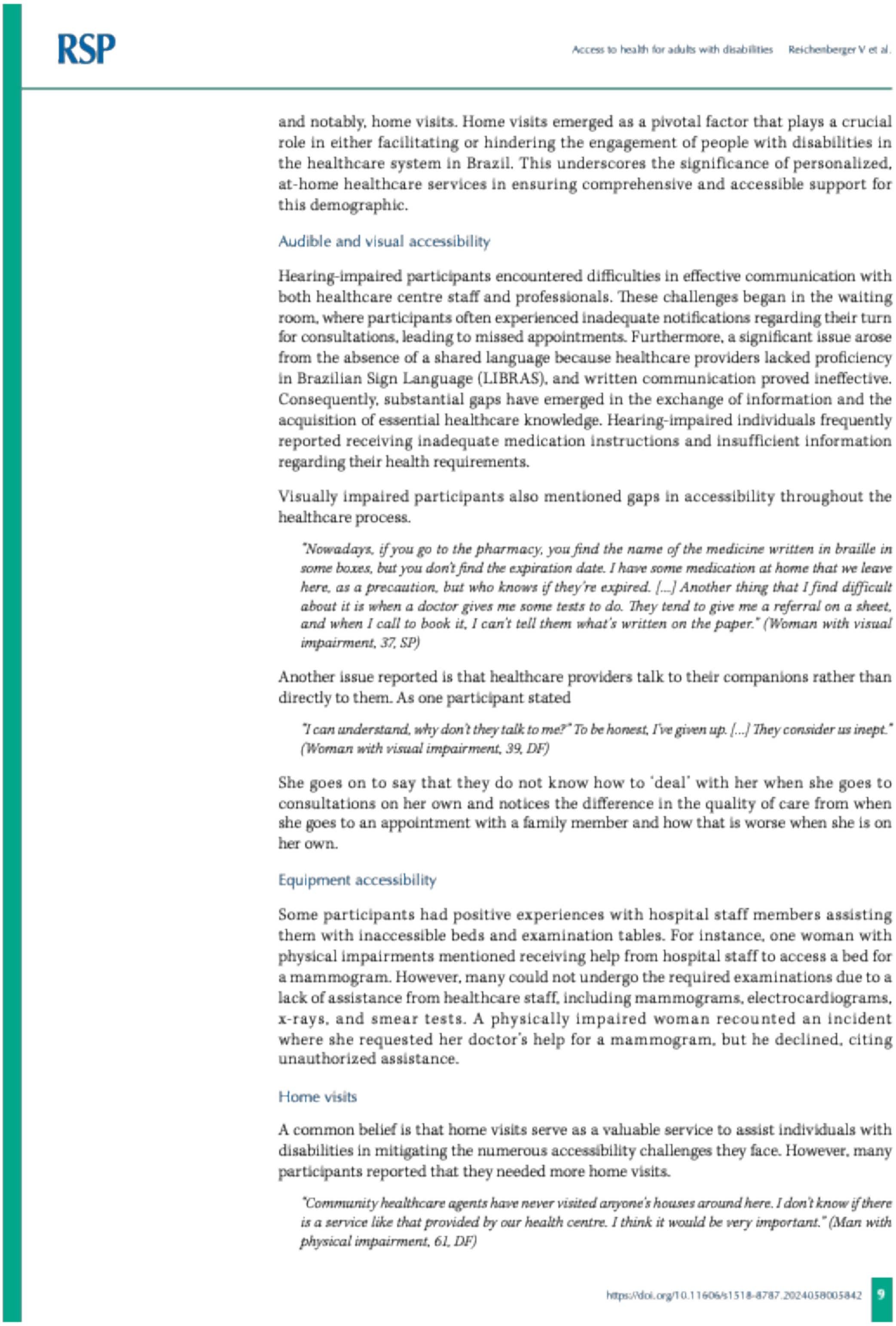
> *"The medication that I have to take daily costs more than what I get paid per month." (Woman with physical impairment, 41, SP)*

As the above quote indicates, participants experience catastrophic expenditures, which were commonly reported. A participant in Distrito Federal with severe depression and suicidal thoughts reported:

> *"I have a physical problem and mental health issues. And the doctor comes to me and says, 'I can't give you this medication because you don't have the money to buy it.' It's brutal for me to hear that from someone who deals with health, that they invariably condemn me to be unhealthy because I don't have money." (Woman with physical impairment, 47, DF)*

Ability to Engage (Audible and Visual Accessibility, Equipment Accessibility and Home Visits)

Within the Levesque Framework[20] 'Ability to engage' assesses service quality, ensuring correct treatment and referrals, as well as patients' ability to decide and engage autonomously. Inductive categories crucial for understanding patients' ability to engage prominently feature audible and visual accessibility, equipment accessibility,



and notably, home visits. Home visits emerged as a pivotal factor that plays a crucial role in either facilitating or hindering the engagement of people with disabilities in the healthcare system in Brazil. This underscores the significance of personalized, at-home healthcare services in ensuring comprehensive and accessible support for this demographic.

Audible and visual accessibility

Hearing-impaired participants encountered difficulties in effective communication with both healthcare centre staff and professionals. These challenges began in the waiting room, where participants often experienced inadequate notifications regarding their turn for consultations, leading to missed appointments. Furthermore, a significant issue arose from the absence of a shared language because healthcare providers lacked proficiency in Brazilian Sign Language (LIBRAS), and written communication proved ineffective. Consequently, substantial gaps have emerged in the exchange of information and the acquisition of essential healthcare knowledge. Hearing-impaired individuals frequently reported receiving inadequate medication instructions and insufficient information regarding their health requirements.

Visually impaired participants also mentioned gaps in accessibility throughout the healthcare process.

> *"Nowadays, if you go to the pharmacy, you find the name of the medicine written in braille in some boxes, but you don't find the expiration date. I have some medication at home that we leave here, as a precaution, but who knows if they're expired. [...] Another thing that I find difficult about it is when a doctor gives me some tests to do. They tend to give me a referral on a sheet, and when I call to book it, I can't tell them what's written on the paper." (Woman with visual impairment, 37, SP)*

Another issue reported is that healthcare providers talk to their companions rather than directly to them. As one participant stated

> *"I can understand, why don't they talk to me?" To be honest, I've given up. [...] They consider us inept." (Woman with visual impairment, 39, DF)*

She goes on to say that they do not know how to 'deal' with her when she goes to consultations on her own and notices the difference in the quality of care from when she goes to an appointment with a family member and how that is worse when she is on her own.

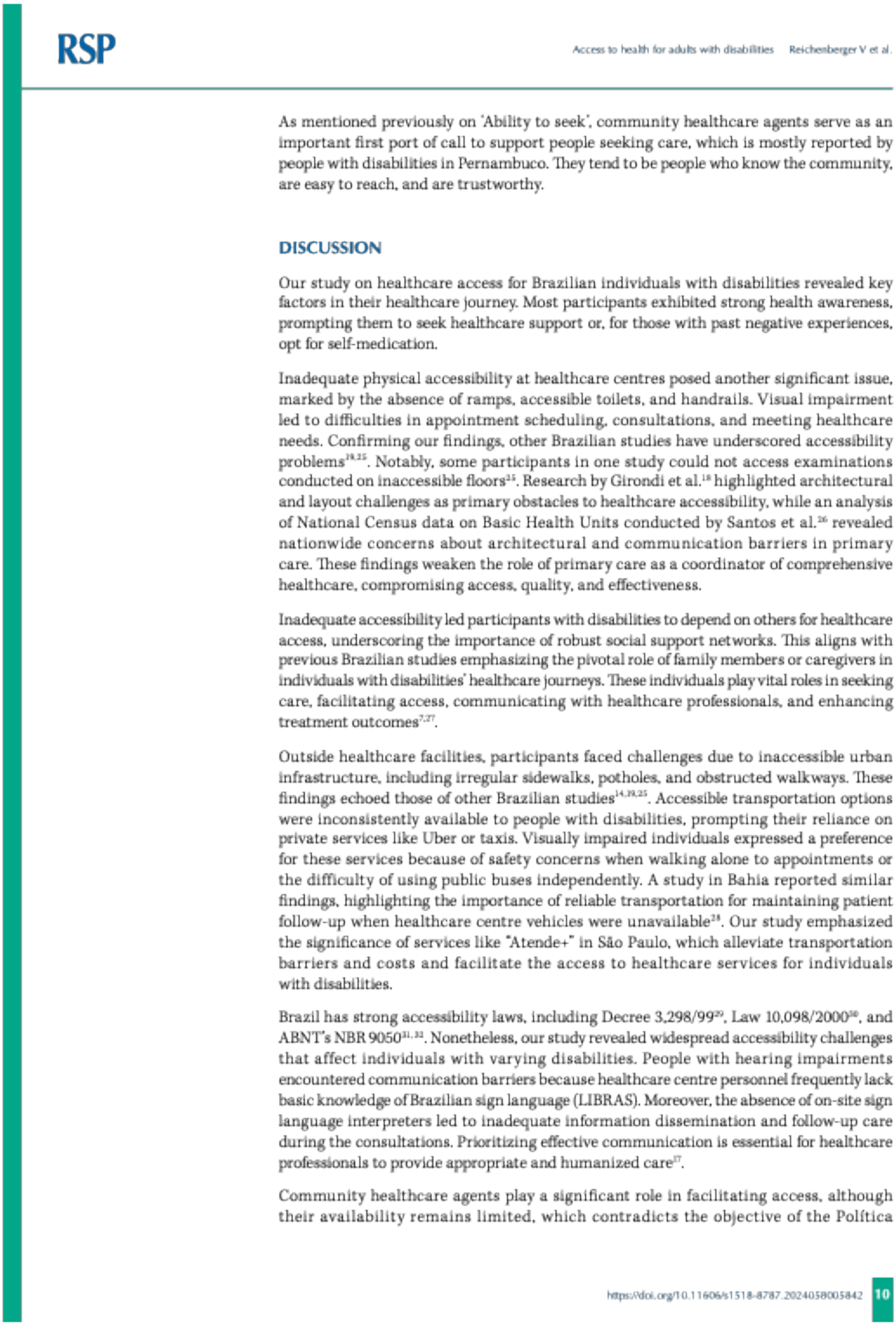
Equipment accessibility

Some participants had positive experiences with hospital staff members assisting them with inaccessible beds and examination tables. For instance, one woman with physical impairments mentioned receiving help from hospital staff to access a bed for a mammogram. However, many could not undergo the required examinations due to a lack of assistance from healthcare staff, including mammograms, electrocardiograms, x-rays, and smear tests. A physically impaired woman recounted an incident where she requested her doctor's help for a mammogram, but he declined, citing unauthorized assistance.

Home visits

A common belief is that home visits serve as a valuable service to assist individuals with disabilities in mitigating the numerous accessibility challenges they face. However, many participants reported that they needed more home visits.

> *"Community healthcare agents have never visited anyone's houses around here. I don't know if there is a service like that provided by our health centre. I think it would be very important." (Man with physical impairment, 61, DF)*



As mentioned previously on 'Ability to seek', community healthcare agents serve as an important first port of call to support people seeking care, which is mostly reported by people with disabilities in Pernambuco. They tend to be people who know the community, are easy to reach, and are trustworthy.

DISCUSSION

Our study on healthcare access for Brazilian individuals with disabilities revealed key factors in their healthcare journey. Most participants exhibited strong health awareness, prompting them to seek healthcare support or, for those with past negative experiences, opt for self-medication.

Inadequate physical accessibility at healthcare centres posed another significant issue, marked by the absence of ramps, accessible toilets, and handrails. Visual impairment led to difficulties in appointment scheduling, consultations, and meeting healthcare needs. Confirming our findings, other Brazilian studies have underscored accessibility problems[19,25]. Notably, some participants in one study could not access examinations conducted on inaccessible floors[25]. Research by Girondi et al.[18] highlighted architectural and layout challenges as primary obstacles to healthcare accessibility, while an analysis of National Census data on Basic Health Units conducted by Santos et al.[26] revealed nationwide concerns about architectural and communication barriers in primary care. These findings weaken the role of primary care as a coordinator of comprehensive healthcare, compromising access, quality, and effectiveness.

Inadequate accessibility led participants with disabilities to depend on others for healthcare access, underscoring the importance of robust social support networks. This aligns with previous Brazilian studies emphasizing the pivotal role of family members or caregivers in individuals with disabilities' healthcare journeys. These individuals play vital roles in seeking care, facilitating access, communicating with healthcare professionals, and enhancing treatment outcomes[7,27].

Outside healthcare facilities, participants faced challenges due to inaccessible urban infrastructure, including irregular sidewalks, potholes, and obstructed walkways. These findings echoed those of other Brazilian studies[14,19,25]. Accessible transportation options were inconsistently available to people with disabilities, prompting their reliance on private services like Uber or taxis. Visually impaired individuals expressed a preference for these services because of safety concerns when walking alone to appointments or the difficulty of using public buses independently. A study in Bahia reported similar findings, highlighting the importance of reliable transportation for maintaining patient follow-up when healthcare centre vehicles were unavailable[28]. Our study emphasized the significance of services like "Atende+" in São Paulo, which alleviate transportation barriers and costs and facilitate the access to healthcare services for individuals with disabilities.

Brazil has strong accessibility laws, including Decree 3,298/99[29], Law 10,098/2000[30], and ABNT's NBR 9050[31,32]. Nonetheless, our study revealed widespread accessibility challenges that affect individuals with varying disabilities. People with hearing impairments encountered communication barriers because healthcare centre personnel frequently lack basic knowledge of Brazilian sign language (LIBRAS). Moreover, the absence of on-site sign language interpreters led to inadequate information dissemination and follow-up care during the consultations. Prioritizing effective communication is essential for healthcare professionals to provide appropriate and humanized care[17].

Community healthcare agents play a significant role in facilitating access, although their availability remains limited, which contradicts the objective of the Política

Nacional de Atenção Básica[33] of providing comprehensive healthcare coverage. The insufficient funding largely contributes to the inadequate provision of primary care services in local communities, which is consistent with previous research that identified low home visit rates, especially for individuals with chronic health conditions or physical impairments[34].

This study identified challenges in providing equitable healthcare for individuals with disabilities in Brazil, underscoring the importance of healthcare provider training in areas such as communication, accessibility, cultural competency, and understanding the specific needs of individuals with disabilities. Addressing these training needs can contribute to a more inclusive and patient-centred healthcare system in Brazil. For example, the participants highlighted both positive and negative experiences regarding equipment accessibility in healthcare settings. Healthcare providers should be trained to assist individuals with disabilities in accessing necessary equipment and ensure that examinations and procedures are feasible for all patients. The findings suggest that individuals with disabilities may feel misunderstood or overlooked by healthcare providers. Training in cultural competency is crucial for healthcare professionals to understand and respect the unique needs, experiences, and perspectives of individuals with disabilities.

Strengths and Limitations

Strengths and limitations exist in this study, impacting result interpretation. In-depth interviews were conducted by researchers with varying experience levels and training, potentially influencing regional disparities. Additionally, interview methods (face-to-face or online) varied by region, with online interviews posing challenges in rapport building and environmental control. Some Arcoverde interviews were held in the state health department's local centre, possibly introducing bias. On the positive side, the study included diverse participants in terms of age, gender, and disability type. Researchers with disabilities were involved to enhance rapport and data quality.

CONCLUSION

This study provides valuable insights into the multifaceted challenges faced by people with disabilities in accessing healthcare in Brazil. It highlights the importance of comprehensive reforms, improved training, and inclusive policies to ensure equitable and accessible healthcare for all individuals.

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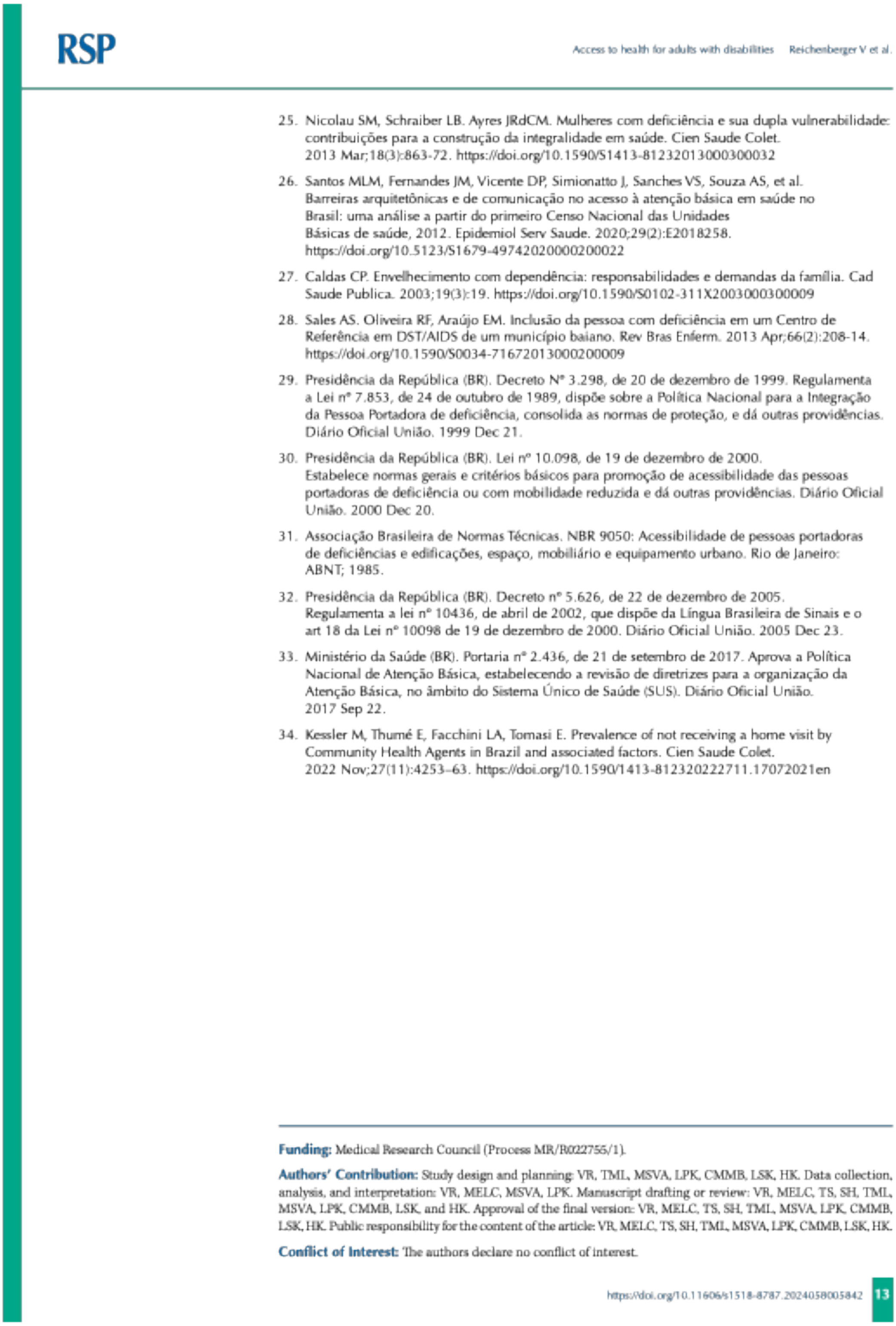

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Conflict of Interest: The authors declare no conflict of interest.

Supporting information [see Appendix 2]
Study information sheet
Interview guide
Consent form

Chapter Five, Paper Three: Participatory visual methods with caregivers of children with congenital Zika syndrome in Colombia

Figure 5: Caregivers of children with CZS filming and being filmed during the Participatory Video workshop in Cali, Colombia

Figure 6: The grandmother of a child with a disability learning how to use a camcorder during the Participatory Video workshop in Cali, Colombia

Preamble

This study aimed to explore the feasibility and acceptability of two different participatory visual methods that use video – digital storytelling and participatory video - within the regional context of Latin America. I had the opportunity and funding to apply these methodologies within the realm of disability studies, specifically focusing on non-disabled caregivers of children with disabilities in Colombia. This study was undertaken with the broader objective of informing the visual methods to be used in the study conducted in Brazil. Given the similarities between Colombia and Brazil, such as comparable Human Development Index rankings (87 for Brazil and 88 for Colombia) [46], this study serves as a critical step in understanding how participatory methods can be effectively employed across different Latin American contexts.

The insights gained from this study are integral to the larger aim of the thesis, which seeks to enhance the understanding of healthcare access for people with disabilities in Brazil through PVM. By testing these methodologies in Colombia, the research not only contributes to the methodological framework but also provides a comparative perspective that enriches the analysis in subsequent chapters. Specifically, the findings from the study informed the decision to use Participatory Video with adults with disabilities in Brazil (Chapter 6, Paper 4), where the collective, participatory nature of the method was anticipated to be particularly effective. This chapter, therefore, serves as a crucial link between the conceptual exploration of participatory methods and their practical application in the Brazilian context, aligning with the thesis's overall goal of promoting inclusive research practices that amplify the voices of people with disabilities.

Through the testing process, I discovered that Digital Storytelling offered the potential to delve more deeply into individual stories within a collective context. When working with adults with disabilities in Brazil (Chapter 6, paper 4), I anticipated that Participatory Video would be more enriching, as it inherently involves a collective approach, allowing individuals to leverage their strengths in creating a shared video. The intriguing aspect I found was the collaborative analysis, where participants collectively identify common themes to represent in the video. I found that more steps throughout the Participatory Video resonates with the principles championed by Paulo Freire [77]. While both methods, Participatory Video and Digital Storytelling, involve the gathering of individuals and embody the principles of dialogue advocated by Freire, Participatory Video takes an additional stride. This method not only brings individuals together for shared discussions but elevates the collaboration to a new level by collectively producing the video. This aligns with Freire's emphasis on co-creation, emphasizing the importance of participants actively contributing to the generation of knowledge and narratives.

The videos produced during these studies were:

1. Digital story - Gabriela venciendo el Zika
2. Digital story - Falta de tacto de algunos profesionales
3. Digital story - La discapacidad en medio de una sala de urgencias
4. Participatory Video – Cali, Colombia

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Thesis Title	Using in-depth interviews and participatory visual methodologies to investigate healthcare access among adults with disabilities in Brazil.		
Primary Supervisor	Loveday Penn-Kekana		

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RESEARCH ARTICLE

REVISED Participatory Visual Methods with caregivers of children with Congenital Zika Syndrome in Colombia: A case study [version 2; peer review: 2 approved, 1 approved with reservations]

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Abstract

Background: This study explores the acceptability and feasibility of the use of two different Participatory Visual Methods (Participatory Video and Digital Storytelling) in gathering information on the experiences and perspectives of carers of children with Congenital Zika Syndrome within Colombia.
Methods: Participatory Video was used to assess the impact of the Juntos parent-support intervention in the lives of carers, and Digital Storytelling was used to explore the healthcare access for these children. In-depth interviews were conducted to probe participants on their views of these methods.
Results: One Participatory Video was produced and four Digital Stories. Of the initial eight caregivers who took part in the Participatory Video process, four completed both the Digital Storytelling process and an in-depth interview about their experiences. The main factors shaping participants' experiences related to the skills learned in making the videos, the feeling of collectiveness and the control over the processes.
Conclusion: Women with children with Congenital Zika Syndrome have reported feeling marginalised and misunderstood in daily life. This case study found that Participatory Visual Methods is acceptable and feasible. Moreover, these approaches can support groups in different aspects, such as providing a space to share their stories creatively, hear others in similar situations as them and increase the feeling of community.

Open Peer Review

Approval Status ✓ ? ✓

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3. **Andrea Mantsios**, Public Health Innovation & Action, New York, USA

Any reports and responses or comments on the article can be found at the end of the article.

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Keywords
Participatory Video, Digital Storytelling, Participatory Visual Methods, Congenital Zika Syndrome

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REVISED **Amendments from Version 1**

We have updated that the main researcher is 'of Brazilian descent' instead of stating she is 'Brazilian'.

In the first paragraph of the results, a new sentence now states: "The other four participants did not take part in the DST and in-depth interview because of lack of time and no access to technological devices."

In the first paragraph under 'Learning and discovering new skills' in the results, a new sentence now states:

"All of them, but one participant, had smartphones and had previously experienced taking pictures and making videos on their phones."

Within the same paragraph, we have also added the words "cinematographic techniques" to clarify new skills that were learned.

We have added the age group and occupation of the participants after their quotes to support the readers.

In the last paragraph of the discussion, we have added a sentence that states: "Additionally, only four participants were involved in both methods, forming the basis for this case study. Therefore, the results cannot be extrapolated to a larger group."

Any further responses from the reviewers can be found at the end of the article

Introduction

Participatory visual methods (PVM) are approaches in which research subjects develop visual material as part of the research process. PVM have roots in anthropology, as anthropologists have often used visual mediums to communicate intangible aspects of culture within their research[1]. PVM create data that are participant-generated and give power to the participant[2], building a collegiate relationship between the researcher and the participant. This means that by working together, participants and researchers bring in different skills in a process of mutual learning[3]. Accordingly, PVM can lead to a reframing of the issues discussed and generate learning from both sides, participants, and researchers alike[4–6].

These participatory methodologies sustain the concepts of Paulo Freire who stated that health and its social determinants should have a wider vision and understanding, where dialogue should be promoted[7]. As such, an appreciation of the lay knowledge and effective social participation is needed when collecting data on needs, access and impacts[8]. As described in the WHO Toolkit on social participation, promoting social participation is important for an equitable distribution of power[9], including during the research process. It is especially important among marginalised people, who can then implement their own findings based on local needs[10]. As an example, Caroline Wang described photo novellas as a way of seeking empowerment of the participants, who understand their communities best, as they identify their own issues; participatory visual methods such as photo novellas are aimed at individual change as well as improvement of the quality of life of the community[11]. These participatory research methods complement Paulo Freire's concept of '*concientização*' ("conscientization"), which means that the more people understand the issues within their community, the more they are in a position of power to create change[7]. Participatory approaches are therefore important research tools; however, they require additional expertise, planning and resources. Consequently, they are often not used, particularly in low-resource settings or in relation to marginalised groups such as people with disabilities[12].

Two different PVM were used in this study, digital storytelling (DST) and participatory video (PV). Both processes involved a stage of reflection through group dialogue, helping to build on the stories of caregivers through sharing and listening[13,14]. Participants then communicate these stories through videos. DST is a process where participants create narratives telling their own stories, using a compilation of still images, videos, audio, text, and music[10]. PV, on the other hand, involves a collaboration between participants to create group-based videos, where participants are involved in different way in crafting the video[15]. A scope of the literature found that participatory visual approaches are most frequently used to explore the views and experiences of groups and have less commonly been used to evaluate interventions. In this paper we consider the acceptability, feasibility, and potential added value of the use of both methods by caregivers of children with congenital Zika syndrome (CZS) in Colombia.

The Zika epidemic struck in 2015, resulting in thousands of children born with microcephaly and other manifestations of CZS in Brazil and other countries in Latin America[16,17]. These children experience a range of health conditions, that include physical, sensory, and cognitive impairment. Consequently, they have high health care needs, which must be met from a broad range of providers, such as physiotherapy, speech and language therapists, audiologists, and occupational therapists[18]. In addition, families are crucial to supporting the complex care needs, and they may experience strain, emotional pressure, and time constraints[19,20]. Colombia reported 11,944 Zika cases among pregnant women by April 2016 and was the second-most affected country after Brazil[21].

Health responses initially focussed on clinical needs of children with CZS; there was also a need to support caregivers in improving their skills to care for their child, as well as to provide psychosocial support to caregivers[22]. To fill that needs gap, the Juntos programme was developed. Juntos is a participatory group programme designed for caregivers of children with CZS based on "Getting To Know Cerebral Palsy"[23,24]. The participatory programme targets caregivers in a support group setting and has been found to offer many important benefits, including improved understanding, confidence and self-esteem, that result in improved care for the child[25]. Juntos was developed and piloted in Rio de Janeiro and Salvador in 2017. It was then adapted and pilot-tested in the Colombian context in 2019. To pilot Juntos for use in Colombia, data were collected from caregivers on lived experience and feasibility of implementation of Juntos, through pre-post intervention questionnaires, in-depth interviews[26] and PVM. The feasibility of the intervention is reported elsewhere[26]; this paper reports on the use of PVM while evaluating the intervention.

The aim of this study was to explore the acceptability and feasibility of the use of two different PVM in gathering information on the experiences and perspectives of carers of children with CZS. PV was used to assess the impact of the Juntos parent-support intervention in the lives of carers, and DST was used to explore the healthcare access for these children. In-depth interviews were conducted to probe participants on their views of these methods.

Methods

Data for this paper are drawn from participant and researcher experiences of the PV and the DST processes using grounded theory. These were captured through observations and semi-structured in-depth interviews with participants.

Participatory video

The PV process was conducted in Cali, Colombia in September 2019. The aim of the PV was to explore the impact of the Juntos programme on caregivers' lives. A group of 11 Colombian caregivers of children with CZS who had taken part in the Juntos programme were approached to take part. These 11 caregivers had formed a group on WhatsApp and were contacted by one of the Juntos facilitators present in the WhatsApp group about the participatory video. Of the 11 caregivers contacted, eight agreed to participate in the process and three refused to participate due to lack of availability. Following the InsightShare[27] methodology from which the facilitator did her training, a one-day workshop was led by the first author (VR). It was held at a local NGO office where the eight caregivers attended with their children. Participants consisted of six mothers, one grandmother and one sister of children with CZS.

The PV process involved a story circle, where the participants each shared their experience of the Juntos programme and how it impacted their lives. On the same day, they were taught how to film by an experienced filmmaker and facilitator (VR). With one camera available, each caregiver took turns filming another, singing to their child. They learned how to start and stop the camera, zoom, and check the sound. They then watched each practice video to understand and identify what they would want to re-create visually for the final video. Participants jointly decided through storyboarding what would be discussed in the final video, and what footage would be shot. A collective decision was made by the participant group that two caregivers would talk while others would either film or show visually what was being said in front of the camera (e.g., how to feed their child, how to play, how to make specific props learned through Juntos). All caregivers contributed to this process. Editing was then discussed, and the facilitator (VR) edited the film according to the suggestions. The final version of the film was agreed through dialogues among the facilitator and the caregivers involved, who explained what music, texts, and effects they wanted in the film. The final version was uploaded and shared with caregivers to use as they wish. The video is available in the *Extended data*[28].

Digital storytelling

The DST project was conducted online in September 2020, following the Story Center[29] methodology at which the facilitator did her training. Of the eight mothers who took part in the PV process, six went on to participate in an initial online story circle which was undertaken through the Zoom platform, led by the first author (VR). The digital stories explored the experience of healthcare access for children with disabilities in Colombia, including reported facilitators and barriers.

During the story circle, participants shared their child's story on healthcare access and identified a specific story that they would like to make a video about. They were then shown examples of digital stories, so they could explore how they could portray their stories visually. One week later, another session took place online where caregivers read their story and gave feedback to each other. From there, caregivers collected photos and videos to portray their story, which were sent to the facilitator (VR). Editing was completed by the facilitator, who closely followed what the participant suggested. The videos were then shared among the caregivers. Of the initial six who took part in the story circle, four completed the digital stories and three have available videos to share.

The videos are available in the *Extended data*[28].

Semi-structured in-depth interviews and researcher observation notes

In total, four in-depth semi-structured interviews were conducted with participants who took part in both the digital stories and PV. Questions were asked about both methods: what participants thought of the process; how they experienced the processes; and their thoughts on the outcome. Questions included topics such as empowerment and extent of ability to communicate their message. The interviews were all conducted in Spanish by an experienced qualitative researcher (VR) via Zoom and lasted approximately 45 minutes to one hour each. All interviews were transcribed verbatim and kept in Spanish for analysis to prevent losses in translation. Transcripts were returned to participants to verify that they agreed with the content before analysis. The lead researcher's (VR) observation notes were also included in the analysis, which included details such as the involvement of the participants, the different reactions and conversations held around the process. All transcripts and observation notes were coded manually. Coding was iterative: central themes were identified as they emerged, refined, and expanded through the coding process[30].

One female researcher (VR) was involved in all three phases of the study. She has previous training in both PV and DST, as well as qualitative research. She is a research assistant and PhD candidate at the London School of Hygiene and Tropical Medicine. She is of Brazilian descent and speaks Spanish fluently. She is not disabled herself and is not the carer of a child with disabilities.

Ethics

Prior to commencing the interviews, participants were provided full information about the study, any queries answered, and written ethical consent obtained. An additional oral ethical consent was obtained at the end of both PV and DST, where participants informed the researchers whether they consented to the videos being shared/used.

Full ethical review and approval was granted by the LSHTM Ethics Committee and the Ethics approval for the study was granted by the London School of Hygiene & Tropical Medicine (LSHTM) (No 15986 /RR/ 11098) and Comité de Etica e Investigacion Asistencia Cientifica de Alta Complejidad (CEIACAC) Bogota (No CEI-022-19).

Results

One PV and four digital stories were produced. The focus of the PV was an evaluation of Juntos, while the focus of the DST process was healthcare access. Of the initial eight caregivers who took part in the PV process, four completed both the DST process and an in-depth interview about their experiences. The other four participants did not take part in the DST and in-depth interview because of lack of time and no access to technological devices. Both participatory visual methods were acceptable and feasible, with key benefits identified in terms of the skills used to make the videos, the feeling of collectiveness and the control over the process.

Learning and discovering new skills

None of the research participants had used a camera recorder before, and all reported using a camcorder as a new experience. All of them, but one participant, had smartphones and had previously experienced taking pictures and making videos on their phones. It was observed by the facilitator that some of the caregivers in the PV workshop were initially resistant to trying to use the camera recorder. However, once they did, and watched their videos again, the delight of watching what they filmed was evident through their facial expression, laughter, and conversations about the videos. One of the caregivers, the grandmother of one of the children (61+ years old, housewife), had little experience using any sort of technological device. She showed a particular resistance in the beginning, but also the most pride in using the camera. Other caregivers photographed her as she filmed holding her granddaughter in her arms. Two caregivers were given the responsibility of filming the PV, and when asked further questions on cinematographic techniques such as angles and ways of filming, she showed an interest in video creation.

> "I learnt a lot, not only how to film but also just exploring my story in a different way, more creatively. Having to think about what I wanted to say and how I can show it in a video." Participant 3 (30–40 years old, housewife)

Specifically, from the DST process, one participant mentioned realising she both enjoys and has a skill for writing narratives. She continued saying she had plans for doing something in the future to support parents with children with disabilities, but had not known what that would be exactly. She felt more in control of what steps to take next and what that journey might be: "After writing the narrative, I realised that I would love to write a book about my son and our story." Participant 1 (26–30 years old, housewife)

The collective and building community

The caregivers who took part in the PVM already knew each other from the 10-week Juntos programme. The structure of both PV and DST meant that participants reflected on common themes and built on top of each other's stories, while having common outcomes to work towards (a digital story each or a PV). Particularly for the PV process, participants were given the space to tell one or two caregivers' stories through a film made collectively, but they decided to change that format to something that suited them better. Through storyboarding, they derived aspects that were common to most caregivers to be portrayed in the video and made sure to include different representations (a mother feeding her daughter orally, and a mother holding her child's gastrostomy tube). The facilitator could observe the enthusiasm of portraying their stories as one united group. It also provided a form of empowerment. For example, mothers who might otherwise shy away, wanted to be in front of the camera, mentioning they would be representing not only themselves but all mothers who may need to feed their children with a gastrostomy tube.

During the editing process, it was clear how the feeling of collectiveness and community came through. In PV, the facilitator was asked to add a slow-motion effect to one footage of all the participants walking, as they wanted to portray the strength they have in caring for their children; just like heroes are shown in films. In the digital stories, after watching each other's videos, the participants wanted certain sections to be re-edited, so they looked more like the others, searching for similarities and unity. There was a feeling of empowerment in the collective.

> "You don't just feel like one mother, but you are *the* mothers of Cali." Participant 2 (30–40 years old, housewife)

Adding to this feeling of community, the processes provided a space for caregivers to learn from each other and that way, change their self-perception and build strength. Their stories were heard and watched, and they could also hear and watch what others shared and made videos about.

> "Participatory video is a way of expressing ideas collectively. I liked it, it was great to learn from other people's stories and understand what is important for each one. It also supported me in understanding the journey I'm going through." Participant 3 (30–40 years old, housewife)

> "In digital storytelling, it was nice to tell and hear other people's stories, we get to know each other better. I didn't know how [one mother] was so resilient and what she went through in the hospital when her daughter got sick!" Participant 1 (26–30 years old, housewife)

> "I enjoyed watching the different digital stories and learn more in depth what [the caregivers] went through. I thought I knew so much about the other mothers, but I realise there's so many stories that haven't been told. We all have so much to say." Participant 3 (30–40 years old, housewife)

Through hearing these stories, participants felt they were not alone and learned ways to overcome similar situations they may face in their day-to-day life.

Control over the process

All caregivers reported feeling appreciated by having their ideas not only heard but implemented into their videos. They also expressed the importance of having a unique role within the different processes. Every caregiver was able to frame their stories and participate in the way they preferred.

> "I'm timid, but I was able to contribute to the participatory video through sitting with [my child] and feeding her while somebody filmed us. I didn't need to talk in front of the camera. I really liked that; I was able to contribute in my own way." Participant 2 (30–40 years old, housewife)

> "I like the way we each could express ourselves in different ways, so some mothers talked, the others were filmed feeding their children or playing. So, there was no need for everyone to do one thing, they could pick and choose within the process what they preferred." Participant 3 (30–40 years old, housewife)

Participants were given a chance to personalise their involvement, and all caregivers were involved in storyboarding, with two leading the writing. Unlike traditional interviews, where you are expected to respond to questions posed, in a PV or DST process, you can contribute equally in other ways. Once the story was validated, four caregivers filmed the narrative (two spoke and two filmed), while the others organised the props and scenarios needed to represent the story visually. In the DST process, participants saw many examples of digital stories to be able to get ideas to create their own, and had it re-edited by the facilitator until they were fully satisfied with the outcome.

Participants reflected on the role of the facilitator, and how explaining the process as clearly and transparently as possible was key to feeling like they were truly in charge of the outcome of the videos. Fieldnotes by the facilitator reflected on the need to let go of expectations and rules attached to the different steps. For it to be a truer participatory process, the facilitator let the participants shape the process to make it theirs, while still needing to stick to the research question. The facilitator kept the "ladder of participation" in mind, where the lowest level is non-participation, the next level is partnership and the highest is effective participation[31]. With every request to adjust the process, the facilitator felt she reached a truer level or partnership between herself and the caregivers. To have reached a higher level of participation, closer to effective participation, some things should have been decided together prior to starting the PVM, such as which PVM to use and what research question would be asked.

> "I felt in control, and I could watch back and give instructions to [the facilitator]. Especially seeing other examples meant I could say what I wanted in what part of the video, and what music I wanted. After watching [one mother's] video, there was something I liked and [the facilitator] went back and changed it for me." Participant 1 (26–30 years old, housewife)

> "[The facilitator] was there but I didn't feel like [she] was imposing anything, we decided what we wanted and [she] helped us build it. The only thing I might have preferred was to talk about my pregnancy in the digital stories instead of health care." Participant 4 (30–40 years old, housewife)

When comparing both methods, PV provided participants with more autonomy and individualised contribution. Within the process of DST, all participants needed to record an audio and pick visuals for the video, meaning there was less space for adjustment. While in PV, no one was obliged to do any of the steps. If caregivers did not want to share their story, they did not need to, and, as mentioned previously, they could contribute in the way they wanted.

Discussion

Both PVM approaches were found to be acceptable and feasible to implement with a group of caregivers of children with CZS in Colombia. Moreover, through the two PVM used, these women who have reported feeling marginalised and alone in many aspects of life[32], were able to find a space within these processes where they were heard and appreciated for being the experts in talking about their own lives[33]. PVM appeared to have the capacity in this case to create what Freire calls "conscientization", providing participants with an active role in understanding and reflecting critically on their community and life. This can lead to tackling oppression, through empowering people to question their condition and encouraging dialogue[7]. The importance of using participatory methods in research is well recognised, including with respect to issues around disability. However, practical constraints, such as lack of tools, skills, budget, time and planning often constrain the use of participatory approaches, particularly in low- and middle-income countries (LMICs)[12]. This case study shows that PVM are feasible and acceptable to use in this group of caregivers of children with disabilities in Colombia, even though they had very limited videography experience. The participants were not people with disabilities themselves, so that adjustments in methods were not needed. An important factor supporting feasibility was that the process was facilitated by a trained videographer who was also a qualitative researcher and Spanish speaker. Participation was particularly observed during data collection, whereas the analysis (video editing) was led by the videographer, but with high levels of input from the participants.

PVM provide space for dialogue in many forms, such as dialoguing in a group and in the video itself. In this project, importance was given not only to expressing oneself but also being heard and hearing others. Low and colleagues talk about the act of being listened to as being one of the main transformational effects for individuals taking part in a process such as DST[34]. Many facilitators have identified hearing and being heard as one of the main empowerment aspects of these methods as well; having a safe and supportive space to share your story, regardless of who will watch the final films[35,36]. This was also observed by the facilitator in this study.

Recent approaches define empowerment as a change in self-perception and increased control over different areas of one's life[37,38]. This definition of empowerment encapsulates what was reported from this study, where participants' awareness of themselves and their own community grew through the process, as they learned from one another and picked up new skills that may lead to further outcomes, such as the mother who now wants to write a book for other caregivers of children with disabilities. This form of empowerment in participants has also been seen in previous studies involving PVM[39–42]. Within this case study, DST and PV have the common goal of empowering individuals and their communities, with an emphasis on the process over the product[43,44]. In their interviews, participants clearly focused on the process of dialoguing and making the videos, more than the final film itself. The act of giving participants a tool that they can themselves use to create, instead of creating something for them, is very powerful. This has been discussed by Yoly Gutierrez when explaining the experience of giving a camera to members of the Kayapó Indigenous tribe[45]. Tribesmen described the camera as their "weapon", as it has the power to strengthen them through providing a tool to voice their experiences as well as giving them a medium to communicate with people outside their community[45]. Mtuy *et al.* also discussed this in a Photovoice study conducted with Maasai women, where women felt empowered as they were put in a role of "educators, agents of change and a source of valued information."[46]. In one of her papers, Caroline Wang talks about an empowerment project that took place in Peru, where women used pencils for the first time. That helped build confidence in women who had never used pencils before[11]. Women are recognised and appreciated for being experts in their own lives and communities.

Regarding the role of the facilitator within a participatory process, the facilitator must have the capacity to let go and form a collegiate relationship with the participants[3]. The participants should be able to contribute to shaping certain aspects of the study, with the facilitator there to support that creation[33]. Facilitators should reflect on the nature of oppression and actively tackle it in all stages of participatory research[7]. In this case study, it was decided at the start that the facilitator would edit videos, which was agreed on by participants who had limited time to edit due to many factors, but that the facilitator would work as a 'tool' to create the video as the participants wanted. It is important to have an intimate and non-hierarchical relationship so that participants can be involved and accept the goals of the research project[47]. For this, dialogue and transparency are important in all stages of the study.

The two main limitations of this study that might have restrained the full potential for understanding the experience of PVM, were time and number of participants. Both PV and DST processes for this study were completed over a short period of time due to time restraints. While some PV projects may take months, both PV and DST for this study took 2.5–3 weeks to complete. Additionally, only four participants were involved in both methods forming the basis for this case study. Therefore, the results cannot be extrapolated to a larger group. If more participants were interviewed and involved, more themes may have emerged and would have allowed inter-group comparisons (e.g., differences by gender, age, support from family, etc). Additionally, the structure of the methods themselves may have inhibited more effective form of empowerment or impact. This has been seen in other PVM such as Photovoice projects[48]. One example was the research question of the DST process; one mother made it very clear that she would have preferred talking about her experience during pregnancy rather than focusing the videos on the initial research question, which was on health care access for their children. The other mothers agreed. On a Photovoice project undertaken by Caroline Wang, she points out that the method itself might have "stopped short of engaging participants in conceptualising and participating in action steps needed to address their needs."[40]

Conclusions

Women with children with CZS have reported feeling marginalised and misunderstood in daily life. This case study shows that PVM are acceptable and feasible, and moreover supported this group through learning and discovering new skills, building the feeling of collectiveness, and providing a space to share their stories creatively.

Data availability

Underlying data

As participants are a close group of caregivers in Cali, the content of the interviews includes names of other caregivers and their children, information, addresses and personal stories. Some of the information mentioned are of participants who were not interviewed for this paper; therefore, it would not be ethical to share this information as they have not consented to it.

Extended data

LSHTM Data Compass: Participatory Visual Methods with caregivers of children with Congenital Zika Syndrome in Colombia: A case study, https://doi.org/10.17037/DATA.00002745[28]

This project contains the following extended data:

- La discapacidad en medio de una sala de urgencias
- Falta_de_tacto_de_algunos_profesionales
- Gabriela_venciendo_el_Zika
- PV_Colombia_subs

'PV_Colombia_subs' is a participatory video produced by caregivers of children with Congenital Zika Syndrome in Cali, Colombia. Through the workshop and video production, caregivers explored the impact of the 'Juntos' program on their lives. All participants featured in the video consented to their images and children's images being shared.

'La discapacidad en medio de una sala de urgencias' 'Falta_de_tacto_de_algunos_profesionales' and 'Gabriela_venciendo_el_Zika' are three digital stories where caregivers of children with Congenital Zika Syndrome explore one story of their child's healthcare access journey. The videos were created within the Digital Storytelling structure. All participants consented to their video being shared.

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Supporting information [see Appendix 3]

Wellcome open peer reviewer feedback
Participatory Video first consent form for children (Spanish)
Participatory Video first consent form for adults (Spanish)
Digital Storytelling information sheet and first consent form
Example Digital Storytelling second consent form – same used for Participatory Video

Chapter Six, Paper Four: Enhancing Disability Research Through Participatory Video: Reflections on a Brazilian Study

Preamble

In the pursuit of achieving objective three of this PhD, it became evident that the utilisation of Participatory Video aligns most closely with Paulo Freire's principles of co-production. To explore this further, it was deemed the most appropriate method for the upcoming segment of the research. Through the study conducted to achieve objective two, with the in-depth interviews, a noteworthy observation emerged regarding the use of proxies among people with disabilities in Pernambuco. Caregivers and family members often served as intermediaries, even for participants without speech impairments. This observation prompted a critical decision to explore the application of Participatory Video in Arcoverde (Pernambuco). The aim was to foster greater direct engagement with adults with disabilities, providing them the platform to articulate their first-hand experiences of healthcare access.

This portion of the study applies the International Classification of Functioning, Disability and Health (ICF) framework to contextualise the Participatory Video process, providing a structured lens to explore the interactions between participants' health conditions, environmental barriers, and personal factors in accessing healthcare.

This paper has been submitted to *Qualitative Health Research* and is currently undergoing peer review.

Click here to watch the Participatory Video produced during this study.

Figure 7: Participants learning how to film and interview during the Participatory Video process in Arcoverde, Brazil

Figure 8: Participants creating storyboards during the Participatory Video process in Arcoverde, Brazil

Figure 9: Participants and the researcher during the Participatory Video process in Arcoverde, Brazil

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

SECTION A – Student Details

Student ID Number	1703886	**Title**	Mrs
First Name(s)	Veronika		
Surname/Family Name	Reichenberger		
Thesis Title	Using in-depth interviews and participatory visual methodologies to investigate healthcare access among adults with disabilities in Brazil.		
Primary Supervisor	Loveday Penn-Kekana		

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?			
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Please list the paper's authors in the intended authorship order:	Veronika Reichenberger, Loveday Penn-Kekana, Shaffa Hameed, Tom Shakespeare, Hannah Kuper

Stage of publication	**In press**

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)	Conceptualization; Methodology; Formal Analysis; Investigation; Writing – Original Draft Preparation; Writing – Review & Editing

SECTION E

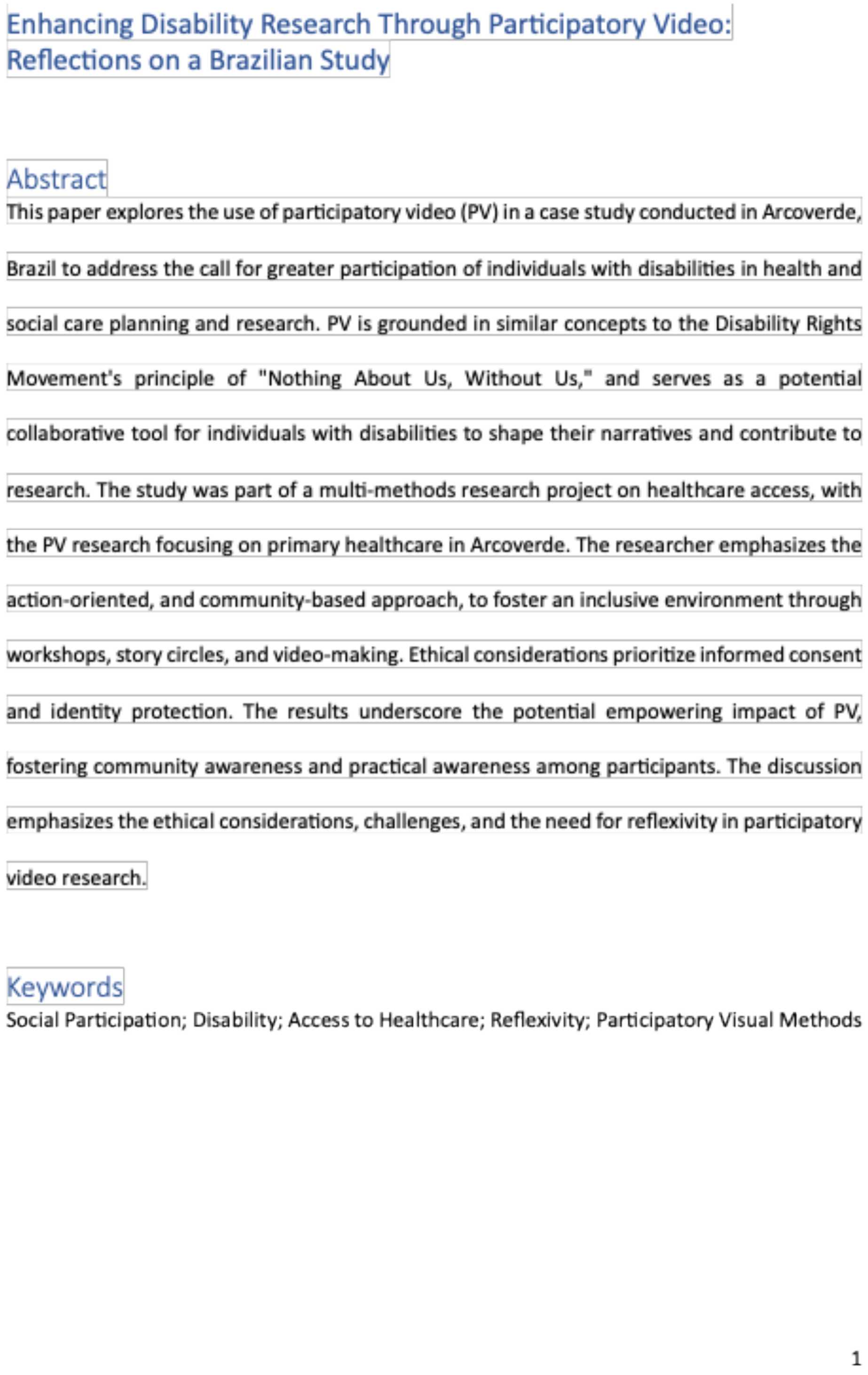
Student Signature	[redacted]
Date	27/03/2024

Supervisor Signature	[redacted]
Date	27/03/2024

Qualitative Health Research

Enhancing Disability Research Through Participatory Video: Reflections on a Brazilian Study

Journal:	*Qualitative Health Research*
Manuscript ID	QHR-2024-0351
Manuscript Type:	Research Article
Keywords:	Social Participation < Community and Public Health, Disability, Disabled Persons, Access to < Health Care, Participatory Visual Methods, Reflexivity
Methods:	Case Study < Research, Emancipatory < Research, Art, Art-Based Research < Research Strategies
Regions, Cultures, and Peoples:	Brazil < South America, South Americans



Enhancing Disability Research Through Participatory Video: Reflections on a Brazilian Study

Abstract

This paper explores the use of participatory video (PV) in a case study conducted in Arcoverde, Brazil to address the call for greater participation of individuals with disabilities in health and social care planning and research. PV is grounded in similar concepts to the Disability Rights Movement's principle of "Nothing About Us, Without Us," and serves as a potential collaborative tool for individuals with disabilities to shape their narratives and contribute to research. The study was part of a multi-methods research project on healthcare access, with the PV research focusing on primary healthcare in Arcoverde. The researcher emphasizes the action-oriented, and community-based approach, to foster an inclusive environment through workshops, story circles, and video-making. Ethical considerations prioritize informed consent and identity protection. The results underscore the potential empowering impact of PV, fostering community awareness and practical awareness among participants. The discussion emphasizes the ethical considerations, challenges, and the need for reflexivity in participatory video research.

Keywords

Social Participation; Disability; Access to Healthcare; Reflexivity; Participatory Visual Methods

Introduction

The participatory video (PV) process is a research method that emphasizes the involvement of participants who are often marginalized or overlooked in traditional research methodologies. This approach is important for its focus on eliciting direct responses from participants recognizing the value of their input regardless of the additional time and effort required to include nonverbal individuals. By incorporating art into research PV offers a unique avenue for engagement particularly beneficial for participants who face challenges with discursive (verbal or written) communication (Barone & Eisner 2011). The inclusion of art as a medium provides a more accessible and expressive platform for these individuals to convey their perspectives and experiences. The integration of digital technologies especially video into our daily lives has made video a compelling tool for engaging people with various sensory impairments in research (Pink 2007). Video's multisensorial capacity—the ability to convey information through visual and auditory means—makes it an effective medium for including individuals with diverse sensory needs. This aspect of PV allows for a more inclusive approach ensuring that research processes are accessible to a broader range of participants.

The use and acceptance of participatory visual methods are increasing in social science, organizational research, and public health contexts (Knoblauch et al., 2008; Warren, 2005). Examples of different types of participatory visual methods, include drawings, photographs (e.g. photovoice), videos (e.g. participatory video), charts, and maps (Atkinson, 2005; Guillemin, 2004; Oakley et al., 1995; Radley & Taylor, 2003; Rich et al., 2000; Yin, 2003). Participatory visual methods are promoted as methods that are useful in collecting data with people with lived experience and exploring their perceptions directly, rather than relying solely on data collected and controlled by the researcher (Rich et al., 2000). These approaches therefore also sustain some of the concepts of Paulo Freire who states that dialogue should be promoted through participation to better understand health and its social determinants (Freire, 2005). Engaging individuals from underrepresented sectors of society, including those with a disability, low economic status, advanced age, different gender, race, or health conditions, can be particularly difficult during policy-making processes (Arnstein, 1969). It has been proposed that participatory visual methods can address these difficulties, by promoting the involvement of people and communities in contemplating and promoting their viewpoints on health, illness, and healthcare across different settings (Lorenz & Kolb, 2009). Another benefit of using participatory visual research is that it supports both the researchers and the people in the focal communities to see problems in a new way and learn from each other (Kolb, 2008; Lorenz & Kolb, 2009; Tritter & McCallum, 2006).

Video is a medium that may be particularly helpful in facilitating participation of individuals within a research process because it involves different processes, such as storyboarding as well as filming itself, which does not limit people to written or reading skills. There are many definitions to participatory video (PV), and this paper will work with one of the understandings suggested by Chris High et al in the "Handbook of Participatory Video" which states that participatory video is *"a collaborative approach to working with a group or community in shaping and creating their own film, in order to open spaces for learning and communication and to enable positive change and transformation"* (High et al., 2012). High and colleagues argue that when it comes to PV, the focus lies not only on the community's involvement in media creation, but also on its ownership and control over the entire process (High et al., 2012). Moreover, it is an empowering process. Indeed, feminist, action-oriented, and community-based research methods strongly focus on fostering involvement that redefines conventional power dynamics (Katz, 1997; Kindon, 2003). Goldman, Booker, and

McDermott (Goldman et al., 2008) explain how PV can "enhance … participatory capacities" and elaborate on how within the process participants actively "negotiate the grounds for participation" (p. 186), suggesting, in line with Freire, that participation is not a given and does not automatically follow from showing up but, rather, must be learned and/or proactively sought (Goldman et al., 2008). This was the guiding philosophy embraced by the researcher of this project. Nevertheless, more evidence is needed to gain a better understanding of how the potential strengths offered by participatory visual methods can be effectively harnessed to enhance disability research.

Participatory approaches are appealing in the disability sector where there is a growing recognition that people with disabilities should have greater engagement in the planning of health and social care as well as in research that often informs this planning (Read & Maslin-Prothero, 2011). The use of participatory methods fits with the Disability Rights Movement's motto of "Nothing About Us, Without Us" and a human rights-based approach (Charlton, 1998; Kuper et al., 2021). Participatory visual methods have the potential to contribute to tackling the exclusion experienced by people with disabilities in many areas of life, including in research and support their inherent right to inclusion in research (United Nations, 2006). Participatory visual methods allow participants to express themselves in a range of different ways, allowing them to communicate their thoughts in different ways (Pink, 2007). As well as giving voice to people with disabilities, these approaches potentially also give people who struggle to communicate verbally other ways to express their views.

This article describes an attempt to use PV to explore people with disabilities' access to care in Brazil. In this study, the participatory visual method - participatory video (PV) – was undertaken as a component of a larger mixed methods research study exploring people with disabilities access to health care services in Brazil. The larger component of the research took place in São Paulo (urban), Santos (sub-urban), Brasilia (urban) and Arcoverde (rural). This component took place in Arcoverde. In participatory research, where data collection, analysis, and interpretation are intricately interwoven, the traditional practice of segregating methods and results is replaced by an integrated approach. This process demands a heightened level of reflexivity from the researcher. Reflexivity becomes integral to the entire research process—shaping how the study is conducted, comprehended, and reported. In this context, the researcher's voice is not hidden, but assumes a more prominent role, diverging from the conventional norms found in standard articles. Reflexivity in this process was undertaken through continuous self-examination and critical reflection on the researcher's positionality, power dynamics, and interactions with participants. Throughout the study, the researcher maintained a reflexivity journal to document her thoughts, biases, and the evolving relationship with the participants. The aim of this paper is to describe the PV process in detail, critically reflecting on the ways to shift power dynamics to foster collaboration between researcher and participants. We offer a comprehensive account detailing the execution of the process, the rationale behind its methodology, challenges faced, lessons learned, and adaptations made.

Participant sampling

For the initial segment of the wider study—the in-depth interviews reported elsewhere—participants were recruited from healthcare clinics and organizations of persons with disabilities (OPDs), followed by snowball sampling. From this group, eleven individuals were selected to participate in additional elements of the research, specifically the participatory video discussed in this paper. Participants from the wider study were initially asked if they were prepared to be contacted about participating in a PV. Most people did not want to be contacted. Of those who agreed, we looked at their profile to make a purposive sample, as we felt it was important to have people with different ages, impairment types and gender take part in the process. Those who agreed were contacted again close to the time of the participatory work to explore if they were still interested in taking part and, if so, provide more details. All but one participant contacted agreed to take part. The one who did not, could not take part due to her availability. It was important to provide all participants with information that financial support for transportation and food would be provided, so that no one was excluded from the study because of financial or transportation barriers. Accessible transportation was also provided where required. The workshop and filming took place over four days. Brazilian ethics approval meant that no one could be paid for their time for participating. When we asked people who agreed to participate to speculate on why others did not, they reported having their own reservations about being in front of the camera and uncertainty about their control over the narrative. Although potential participants were provided with comprehensive information about the participatory video (PV) process, including its purpose, activities involved, and potential benefits and risks, some still felt uneasy about being filmed and unsure about their level of influence. This feedback underscores the need for additional information and reassurance.

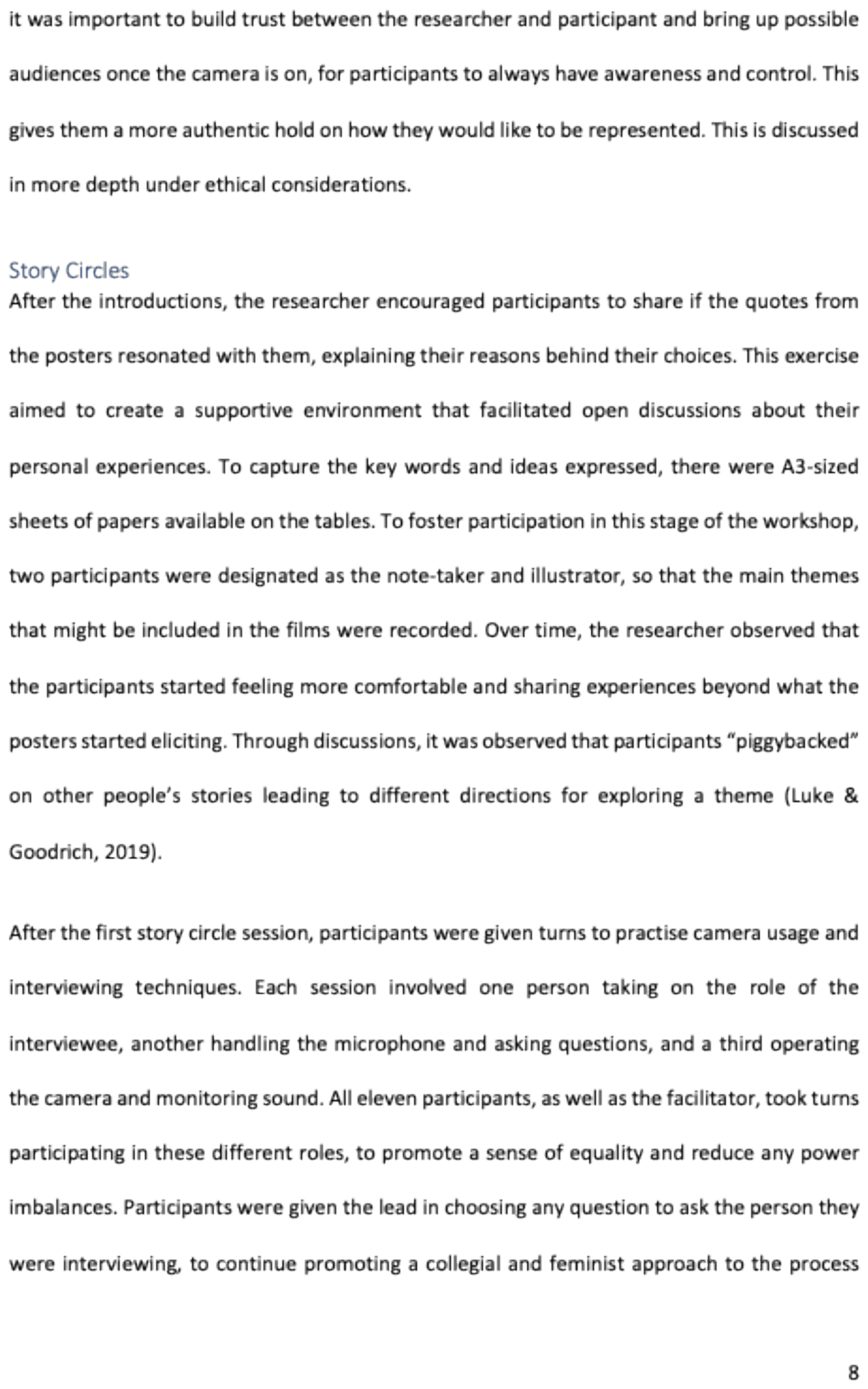
Welcoming

A range of approaches were incorporated to promote active participation to try and achieve the aim of shifting power dynamics and encouraging voice. One strategy was not to set up the room where the workshop would take place, in advance. Instead, the workshop venue was organised collectively as participants arrived.

Additionally, the participants were asked to assist in distributing papers and pens across the tables, and setting up the camera, ensuring that everyone had the necessary materials. Once all the necessary preparations were completed, participants gathered around for introductions, sharing their names and, as an icebreaker, what breakfast they had. This simple icebreaker activity fostered a friendly and inclusive environment and helped to build rapport among the participants.

However, the challenge that faced this project, like many participative projects, is that although the aim was for participants to lead as much as possible, the topic still had to fit within the wider project, which is on primary healthcare access. Quotations were put up on the wall, which contained anonymised transcripts from the in-depth interviews, mostly consisting of quotations that they themselves had shared during the interviews. The goal behind this was to give participants a chance to see what others had said, and to analyse and reflect together, and work as co-researchers. This differed from conventional interviews, where participants are only asked about their own experiences. The researcher encouraged participants to read the quotes and offer support to visually impaired participants in reading them.

The researcher put in place several techniques to try and ensure that participants were feeling comfortable with the camera. It is the researcher's responsibility to mitigate the degree to which participants are self-aware of the camera. Techniques included introducing the camera to the participants straightaway and letting them engage with it. During the welcoming stage of the workshop, the participants were asked to set up the camera, as guided by the researcher, so that they had some control over the camera. By connecting the camera to a TV, everyone had the opportunity to observe the filming process in real-time. Those with a visual impairment were informed about the filming. Emphasis was placed on utilizing both the audio and visual components of the video, allowing each participant to contribute using the sensory mode that best complemented their ability to describe their story. Additionally,



it was important to build trust between the researcher and participant and bring up possible audiences once the camera is on, for participants to always have awareness and control. This gives them a more authentic hold on how they would like to be represented. This is discussed in more depth under ethical considerations.

Story Circles

After the introductions, the researcher encouraged participants to share if the quotes from the posters resonated with them, explaining their reasons behind their choices. This exercise aimed to create a supportive environment that facilitated open discussions about their personal experiences. To capture the key words and ideas expressed, there were A3-sized sheets of papers available on the tables. To foster participation in this stage of the workshop, two participants were designated as the note-taker and illustrator, so that the main themes that might be included in the films were recorded. Over time, the researcher observed that the participants started feeling more comfortable and sharing experiences beyond what the posters started eliciting. Through discussions, it was observed that participants "piggybacked" on other people's stories leading to different directions for exploring a theme (Luke & Goodrich, 2019).

After the first story circle session, participants were given turns to practise camera usage and interviewing techniques. Each session involved one person taking on the role of the interviewee, another handling the microphone and asking questions, and a third operating the camera and monitoring sound. All eleven participants, as well as the facilitator, took turns participating in these different roles, to promote a sense of equality and reduce any power imbalances. Participants were given the lead in choosing any question to ask the person they were interviewing, to continue promoting a collegial and feminist approach to the process

(Kindon, 2003). It was felt important that every step of the PV process provided a space for autonomy and expression. Participants were asked a range of questions, such as "Tell me about your mother," "What is your biggest challenge in health today?" and "How do you describe disability?" This allowed all participants to gain hands-on experience in filming and interviewing. Later, they collectively watched the recorded videos to provide constructive feedback on various aspects including framing, audio quality, and overall effectiveness. This feedback session helped participants understand how filming translates into video content.

The practice sessions were also designed to enable participants to understand the different ways each of them could contribute to the filming process, and participants identifying different roles for themselves was observed over time. For example, one participant, Daniele, quickly demonstrated a talent for interviewing, while another, Josefa, expressed a preference for operating the camera. Petra, a participant with an intellectual impairment, contributed by showing the importance of well-angled ramps and the material of the pavement while someone filmed her; Gabriel, helped with filming and storyboarding, highlighting the need for better transportation.

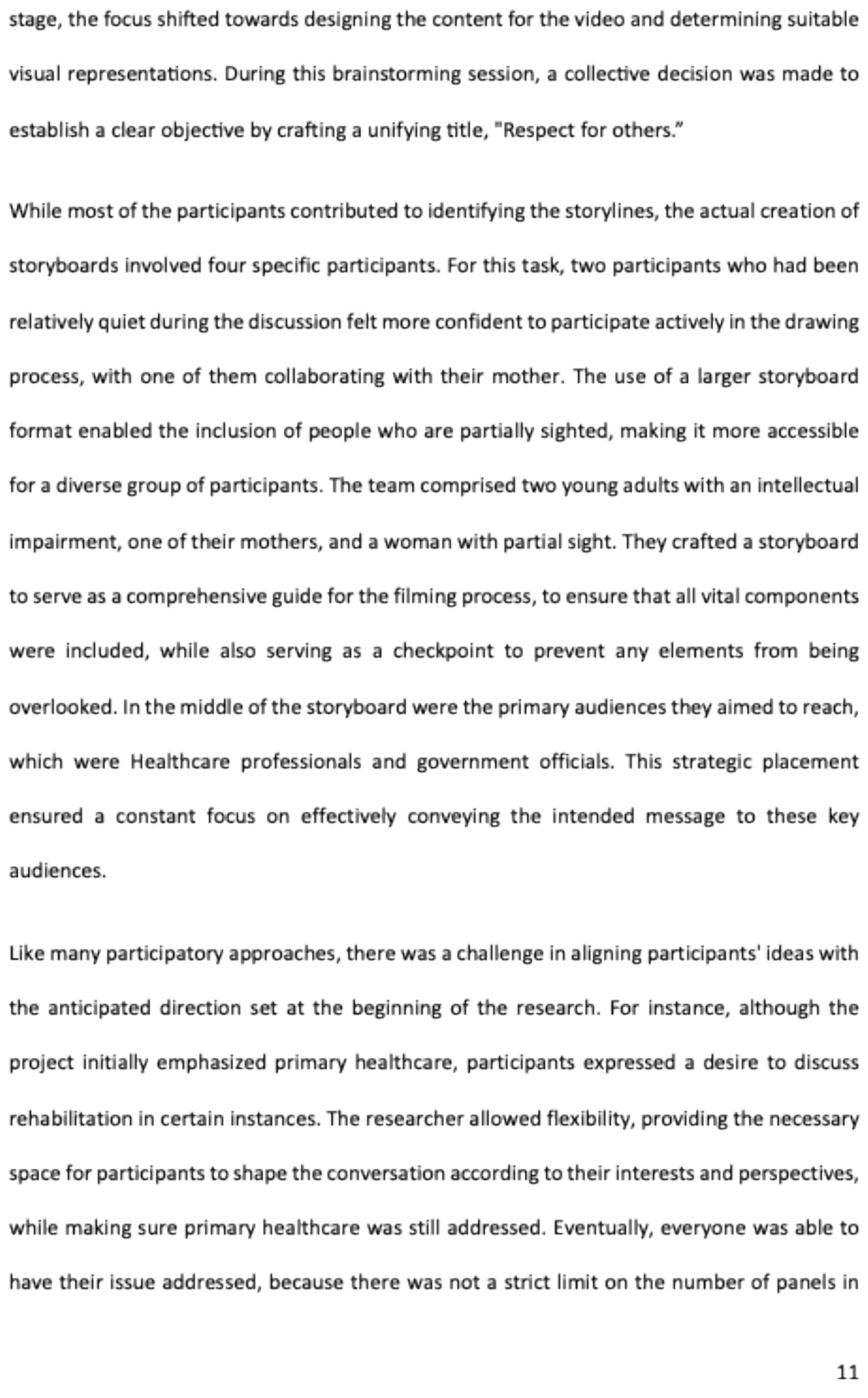
A second story session was held the following day, after participants had the opportunity to go home and reflect on the discussions from the previous day. The focus of the second story circle was on healthcare and disabilities, moving beyond personal experiences to engage in a broader reflection on the reasons why people with disabilities may face poorer health outcomes. Both story circles were organised so that participants had the flexibility to contribute by speaking, writing or through non-verbal communication. For example, Nadjane, who had experienced a stroke and lost her ability to write or walk, used drawings and gesticulation to express that she suffered greatly from stigma. Her son, who had given the in-depth interview because of his ability to communicate verbally, had focused on another of her barriers, transportation, but did not mention the other barrier important to Nadjane – stigma. Nadjane's contribution on stigma led to other participants expanding on their experiences, revealing new themes that would have otherwise been missed and did not emerge in the in-depth interview component of the research project. For instance, two caregivers described how in pre-pandemic times, people moved away from their children with disabilities at a healthcare centre waiting area, as if their disabilities were contagious. From a caregiver perspective, this process was different to their usual interactions as it allowed for various types of participation and provided participants with more time. In those usual interactions, caregivers often found themselves needing to intervene, recognizing that others might lack the patience to truly understand and listen to them.

"I am used to answering on behalf of Gabriel because I know people don't have the patience or the interest to try to understand him. It's a way of protecting him." (Tancleide, mother of Gabriel, who is on the autism spectrum)

As the workshop progressed, the researcher observed that Tancleide shifted away from this approach. She started giving her son more space to speak on his behalf, as she noticed the researcher and other participants were interested in his point of view and were willing to listen.

Storyboarding

A storyboard is a visual representation that depicts the key scenes and shots of a film or video. It helps filmmakers plan and organise their shots before they start filming. Each storyboard panel has a simple drawing with notes about things like camera angles, movements, lighting, and dialogue, making it a helpful tool for the video-making process. During the storyboarding



stage, the focus shifted towards designing the content for the video and determining suitable visual representations. During this brainstorming session, a collective decision was made to establish a clear objective by crafting a unifying title, "Respect for others."

While most of the participants contributed to identifying the storylines, the actual creation of storyboards involved four specific participants. For this task, two participants who had been relatively quiet during the discussion felt more confident to participate actively in the drawing process, with one of them collaborating with their mother. The use of a larger storyboard format enabled the inclusion of people who are partially sighted, making it more accessible for a diverse group of participants. The team comprised two young adults with an intellectual impairment, one of their mothers, and a woman with partial sight. They crafted a storyboard to serve as a comprehensive guide for the filming process, to ensure that all vital components were included, while also serving as a checkpoint to prevent any elements from being overlooked. In the middle of the storyboard were the primary audiences they aimed to reach, which were Healthcare professionals and government officials. This strategic placement ensured a constant focus on effectively conveying the intended message to these key audiences.

Like many participatory approaches, there was a challenge in aligning participants' ideas with the anticipated direction set at the beginning of the research. For instance, although the project initially emphasized primary healthcare, participants expressed a desire to discuss rehabilitation in certain instances. The researcher allowed flexibility, providing the necessary space for participants to shape the conversation according to their interests and perspectives, while making sure primary healthcare was still addressed. Eventually, everyone was able to have their issue addressed, because there was not a strict limit on the number of panels in the storyboard. Some participants believed that certain themes warranted more than one scene for effective representation. Initially, the theme of stigma was added to the storyboard to be portrayed through a re-enactment of Nadjane's stigma experience. However, the group decided to add an additional scene to depict another facet of stigma – the story of Tancleide and Gabriel.

Video making

The subsequent filming sessions were conducted after Storyboarding. Filming took place in three distinct locations decided by the participants: the workshop venue, the rehabilitation clinic, and in front of a primary healthcare centre. By incorporating these diverse settings, participants aimed to capture a comprehensive perspective on the topics discussed during the workshop and support reflection. While the researcher suggested different styles, such as 'acting' or more use of creative resources such as drawing, the group was drawn towards a more 'video reporting' style, a style familiar to many people in Brazil. One participant, Marcelino, who is a wheelchair user, mentioned the importance of accessible transportation throughout the PV and the in-depth interviews, realised he had forgotten to mention an important barrier – the width of doors – while they were filming. He struggled to enter the building because one of the doors was shut. He mentioned "It's so common place I forget to mention it." On a similar note, during the last group discussion, the participants explained how they forget that there is a need to advocate for their needs due to barriers becoming so normalized in daily life. Additionally, hearing from others was very important, to confirm their perspectives and experiences.

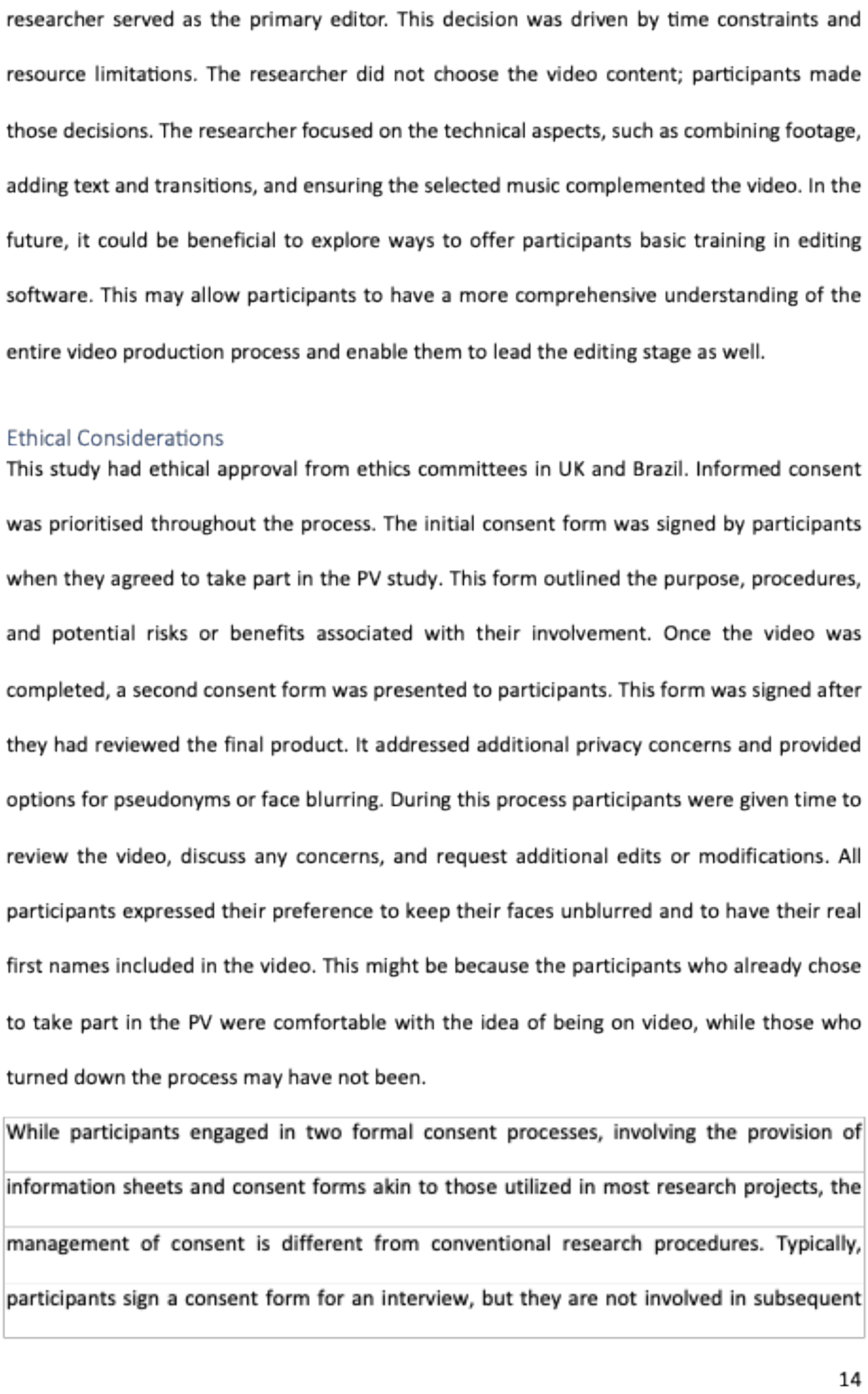
"We go through these struggles every single day, only now am I realizing that other people go through the same things." (Catarina, Petra's mother, who has an intellectual impairment)

Editing

On the third day, the editing process commenced, although there remained some components still to be filmed. It was vital for the participants to observe how the story was coming together and identify any missing elements and to understand how they are being represented through the film so far, providing an option of reshooting or changing anything they were uncomfortable with. To facilitate this, the researcher connected a laptop to a TV screen with speakers, allowing everyone to view and listen the footage collectively. Following the initial screening, the participants watched the footage again, this time with specific focus on identifying any gaps or missing elements. This inclusive process allowed participants to both listen and watch, enabling them to contribute their ideas regarding missing images, creative editing techniques, and text. The collaborative atmosphere fostered a sense of ownership and engagement among the participants. For example, Petra's mother suggested *"We should show an example of what an accessible ramp looks like, how about we film someone going up the ramp at [the local rehabilitation centre]?"*.

Furthermore, the participants collectively decided on a song that would accompany the video. They opted for an inspirational gospel song, a choice that resonated with most of the participants. An instrumental version of the song was added to the video so that it did not overtake the voices of participants. This decision further enhanced the inclusive nature of the project, ensuring that everyone's preferences were considered. After all the components were completed, the following day, the participants gathered to watch the final version of the video.

Participants did not receive training on using editing software during the project, as film editing is a complex technical task that requires sophisticated software. Consequently, the



researcher served as the primary editor. This decision was driven by time constraints and resource limitations. The researcher did not choose the video content; participants made those decisions. The researcher focused on the technical aspects, such as combining footage, adding text and transitions, and ensuring the selected music complemented the video. In the future, it could be beneficial to explore ways to offer participants basic training in editing software. This may allow participants to have a more comprehensive understanding of the entire video production process and enable them to lead the editing stage as well.

Ethical Considerations

This study had ethical approval from ethics committees in UK and Brazil. Informed consent was prioritised throughout the process. The initial consent form was signed by participants when they agreed to take part in the PV study. This form outlined the purpose, procedures, and potential risks or benefits associated with their involvement. Once the video was completed, a second consent form was presented to participants. This form was signed after they had reviewed the final product. It addressed additional privacy concerns and provided options for pseudonyms or face blurring. During this process participants were given time to review the video, discuss any concerns, and request additional edits or modifications. All participants expressed their preference to keep their faces unblurred and to have their real first names included in the video. This might be because the participants who already chose to take part in the PV were comfortable with the idea of being on video, while those who turned down the process may have not been.

While participants engaged in two formal consent processes, involving the provision of information sheets and consent forms akin to those utilized in most research projects, the management of consent is different from conventional research procedures. Typically, participants sign a consent form for an interview, but they are not involved in subsequent

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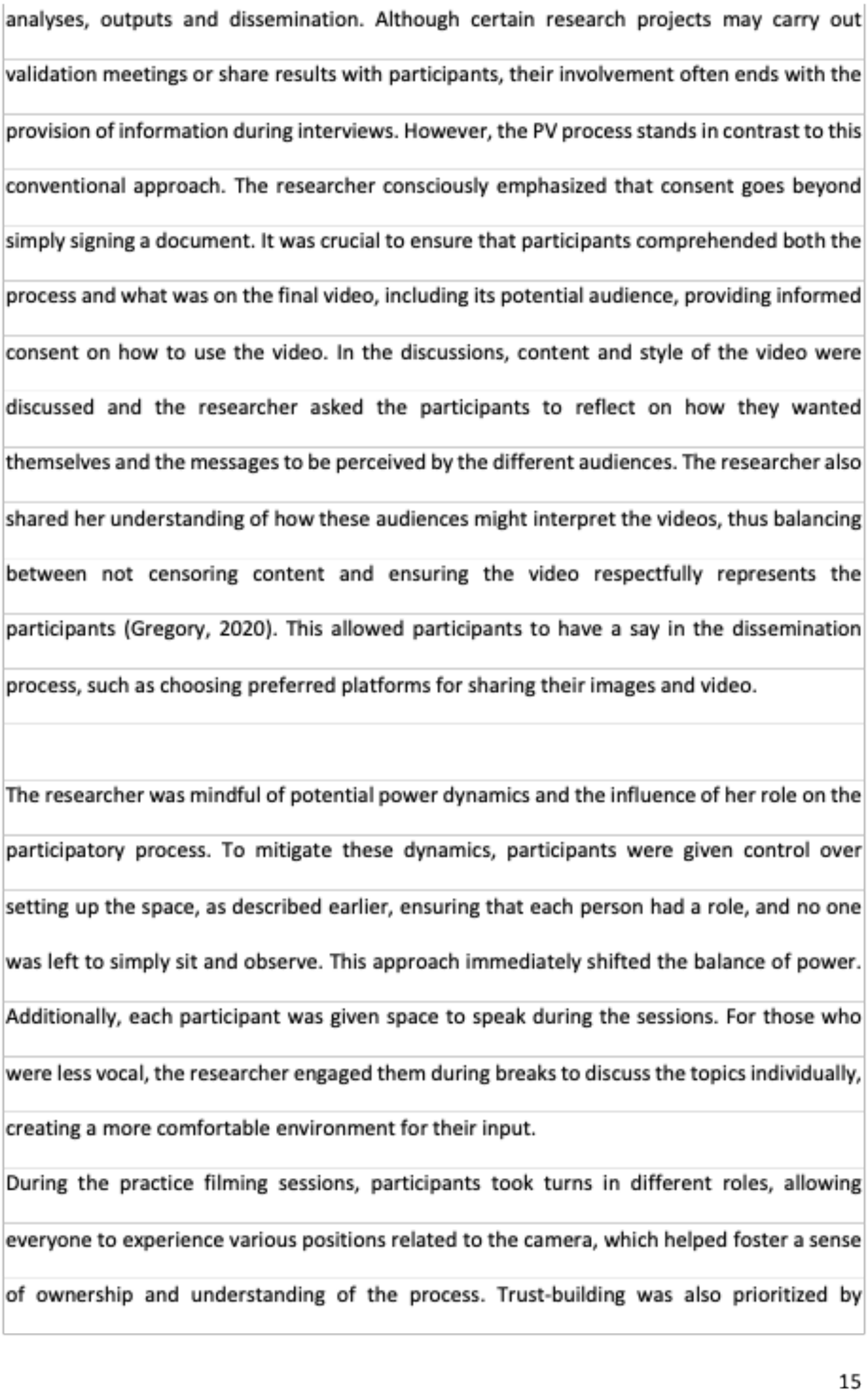

analyses, outputs and dissemination. Although certain research projects may carry out validation meetings or share results with participants, their involvement often ends with the provision of information during interviews. However, the PV process stands in contrast to this conventional approach. The researcher consciously emphasized that consent goes beyond simply signing a document. It was crucial to ensure that participants comprehended both the process and what was on the final video, including its potential audience, providing informed consent on how to use the video. In the discussions, content and style of the video were discussed and the researcher asked the participants to reflect on how they wanted themselves and the messages to be perceived by the different audiences. The researcher also shared her understanding of how these audiences might interpret the videos, thus balancing between not censoring content and ensuring the video respectfully represents the participants (Gregory, 2020). This allowed participants to have a say in the dissemination process, such as choosing preferred platforms for sharing their images and video.

The researcher was mindful of potential power dynamics and the influence of her role on the participatory process. To mitigate these dynamics, participants were given control over setting up the space, as described earlier, ensuring that each person had a role, and no one was left to simply sit and observe. This approach immediately shifted the balance of power. Additionally, each participant was given space to speak during the sessions. For those who were less vocal, the researcher engaged them during breaks to discuss the topics individually, creating a more comfortable environment for their input.

During the practice filming sessions, participants took turns in different roles, allowing everyone to experience various positions related to the camera, which helped foster a sense of ownership and understanding of the process. Trust-building was also prioritized by

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explaining the full scope of the study, including the research questions, the team, the intended use of the results, and how the video contributed to the larger project. Emphasizing the collaborative nature of the research, the researcher made it clear that while she may have expertise in video-making, she did not possess the lived experience of disability and the nuances of healthcare access, thereby acknowledging that the participants were experts themselves.

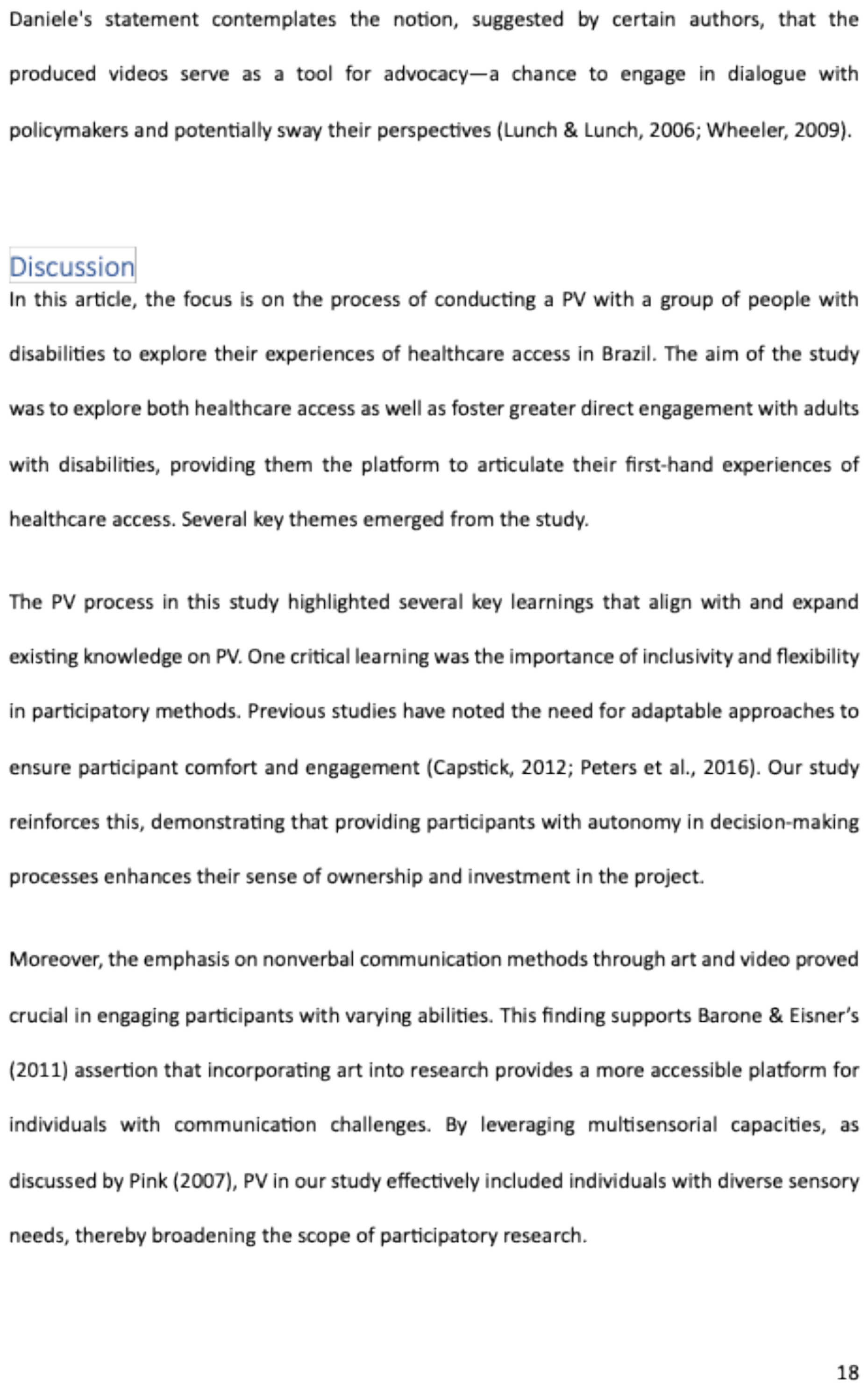
Dissemination

Through the workshop, conversations emerged regarding how the participants wished their videos to be utilized, both by the researcher and by the participants themselves. As a group we discussed the value of highlighting the barriers they face in accessing healthcare services, and participants expressed a strong desire to share the videos with their healthcare workers, including primary healthcare providers and rehabilitation specialists. The videos were uploaded to Vimeo as unlisted, ensuring that only individuals with the specific link could access them. Participants were provided with the links, enabling them to share the videos as freely and with whomever as they desired. Two participants showed the videos to healthcare professionals, one from primary healthcare care and one in her local rehabilitation centre. They also shared the videos with family members, aiming to foster a broader understanding that their experiences are not isolated but shared by others with disabilities. The participants emphasized their interest in showcasing the video in university settings and training programmes, with the aim of educating current and future healthcare professionals and policymakers. They expressed a keen desire for the video to reach as many people as possible, indicating their eagerness for it to be shared on social media platforms.

"Other people will be able to see that my complaints are not just my own, but that other people with disabilities go through the same struggles." (Daniele, 40, female, visually impaired)

An event was organised in Brasilia, Brazil to facilitate the dissemination process of the wider project, in March 2023. This two-day-long event brought together key stakeholders, including representatives from the Ministry of Health, researchers, students, and organizations of persons with disabilities (OPDs). Through the video, attendees were able to hear the participants' first-hand experiences and witness their challenges, such as struggling with narrow doors, uneven pavements, and the re-enactment of stigmatization. The video sparked meaningful conversations among the stakeholders present, leading to discussions about placing people with disabilities at the forefront of research and highlighting the importance of addressing their specific needs and concerns within healthcare systems. Overall, we perceived that the participants' video provided a valuable perspective that resonated deeply with the attendees, which, along with the rest of the study, led to the development of recommendations for a more inclusive and informed approach to healthcare provision. Unfortunately, no funding was available to bring participants from Pernambuco to Brasilia. The participants who took part were invited to watch the dissemination event and were informed of the recommendations that were developed.

"It was very powerful to hear myself on the video, talking about the needs of people with disabilities, knowing that people in the audience can hopefully do something about it." (Daniele, 40, female, visual impairment)



Daniele's statement contemplates the notion, suggested by certain authors, that the produced videos serve as a tool for advocacy—a chance to engage in dialogue with policymakers and potentially sway their perspectives (Lunch & Lunch, 2006; Wheeler, 2009).

Discussion

In this article, the focus is on the process of conducting a PV with a group of people with disabilities to explore their experiences of healthcare access in Brazil. The aim of the study was to explore both healthcare access as well as foster greater direct engagement with adults with disabilities, providing them the platform to articulate their first-hand experiences of healthcare access. Several key themes emerged from the study.

The PV process in this study highlighted several key learnings that align with and expand existing knowledge on PV. One critical learning was the importance of inclusivity and flexibility in participatory methods. Previous studies have noted the need for adaptable approaches to ensure participant comfort and engagement (Capstick, 2012; Peters et al., 2016). Our study reinforces this, demonstrating that providing participants with autonomy in decision-making processes enhances their sense of ownership and investment in the project.

Moreover, the emphasis on nonverbal communication methods through art and video proved crucial in engaging participants with varying abilities. This finding supports Barone & Eisner's (2011) assertion that incorporating art into research provides a more accessible platform for individuals with communication challenges. By leveraging multisensorial capacities, as discussed by Pink (2007), PV in our study effectively included individuals with diverse sensory needs, thereby broadening the scope of participatory research.

Additionally, the study underscored the ethical dimensions of PV, particularly concerning power dynamics and representation. High et al. (2012) and Gregory (2020) emphasize the necessity of addressing power imbalances and ensuring participant control over the narrative. Our approach, which involved participants in every stage from storyboarding to editing, echoes this sentiment and showcases the empowering potential of PV. Addressing power dynamics and representation required the researcher on this study to consciously hand over decision-making power to the participants. This involved ongoing self-reflection on the extent of the researcher's involvement and her role as a facilitator. The aim was to support participants in collecting and presenting their data rather than imposing ideas. This process acknowledged that participants, who might be more accustomed to giving interviews or being in less empowered positions, needed encouragement to take ownership and lead the video-making process. Empowering individuals to engage in different stages of the process ensured that participation was not only holistic but also tailored to their preferences. Therefore, it was important to provide them with a clear understanding of the project and the steps involved in the participatory video process. Building their confidence to film, interview, and record sound allowed them to make informed decisions about their level of involvement and what that involvement would be.

Furthermore, the iterative nature of PV facilitated deeper reflections among participants, as they were able to engage with the content over several days. This prolonged engagement contrasts with traditional interview methodologies and aligns with findings by Bezzina (2023) that participatory methods can offer a more ethical and reflective research process. Through the various stages of sharing their stories, discussing access to healthcare, and determining what to include in the film, participants in our study engaged in ongoing reflection on both their individual and collective experiences, and how best to represent them in the film. The ability to continuously revisit and revise their contributions allowed participants to express more nuanced perspectives, thereby enriching the research outcomes.

The collaborative editing process, although constrained by technical limitations, provided valuable insights into the importance of participant involvement in post-production stages. While technical expertise is required for editing, future research should explore ways to train participants in basic editing skills, enhancing their understanding and control over the final product (Goldman et al., 2008).

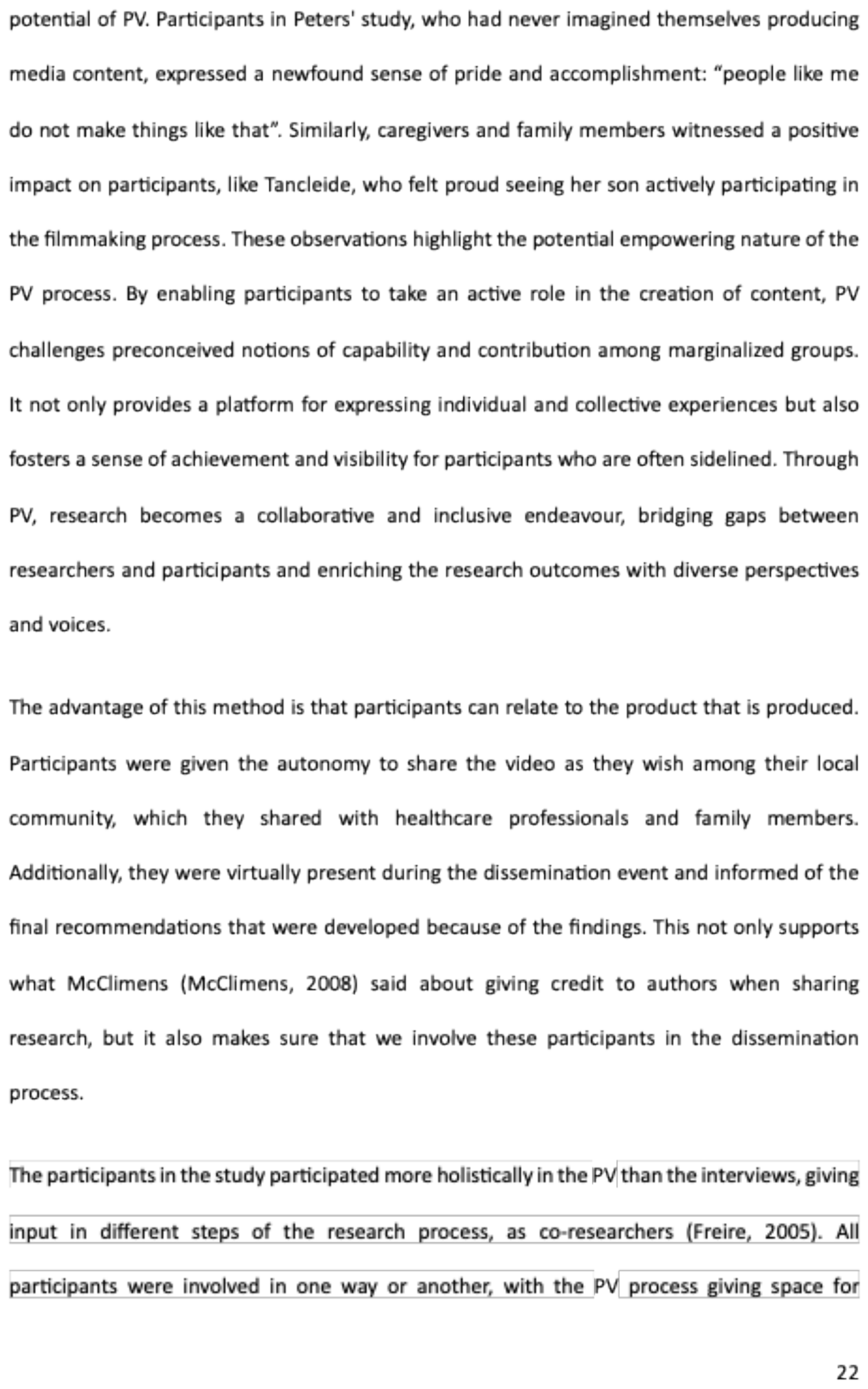
Facilitated Inclusive Participation

What makes a video project 'participatory' is challenging to define and probably is on a continuum. For this project, the topic was clearly defined by the research team, but there was considerable effort to let participants take ownership of the process throughout the workshop, such as setting up the equipment and deciding how they would be involved in the process. The workshop was carefully planned to be accessible and adapted to needs that arose, for example, when one of the participants was non-verbal and could not write.

It was important to acknowledge that this might lead to some deviation from the initial focus on primary healthcare and a shift towards rehabilitation. While it is important to acknowledge the initial focus on primary healthcare, the willingness to adapt and accommodate the participants' evolving ideas ensured that the video reflected their genuine engagement and sense of ownership. This approach fostered a stronger sense of empowerment and inclusivity among the participants, ultimately enhancing the overall quality and authenticity of the content. Three other projects that conducted PVs with people with disabilities expressed the need to adapt the process to the participants' needs (Buchanan & Murray, 2012; Capstick, 2012; Peters et al., 2016). They mention the importance of slowing the pace and creating a more flexible process to adapt to the participants' needs. Capstick (Capstick, 2012) mentions that when conducting a PV process with people with disabilities, reflection and attention is needed to make it more inclusive and accessible.

The PV process is a research method that emphasizes the involvement of participants who are often marginalized or overlooked in traditional research methodologies. This approach is important for its focus on eliciting direct responses from participants, recognizing the value of their input regardless of the additional time and effort required to include nonverbal individuals. By incorporating art into research, PV offers a unique avenue for engagement, particularly beneficial for participants who face challenges with discursive (verbal or written) communication (Barone & Eisner, 2011). The inclusion of art as a medium provides a more accessible and expressive platform for these individuals to convey their perspectives and experiences. The integration of digital technologies, especially video, into our daily lives has made video a compelling tool for engaging people with various sensory impairments in research (Pink, 2007). Video's multisensorial capacity—the ability to convey information through visual and auditory means—makes it an effective medium for including individuals with diverse sensory needs. This aspect of PV allows for a more inclusive approach, ensuring that research processes are accessible to a broader range of participants.

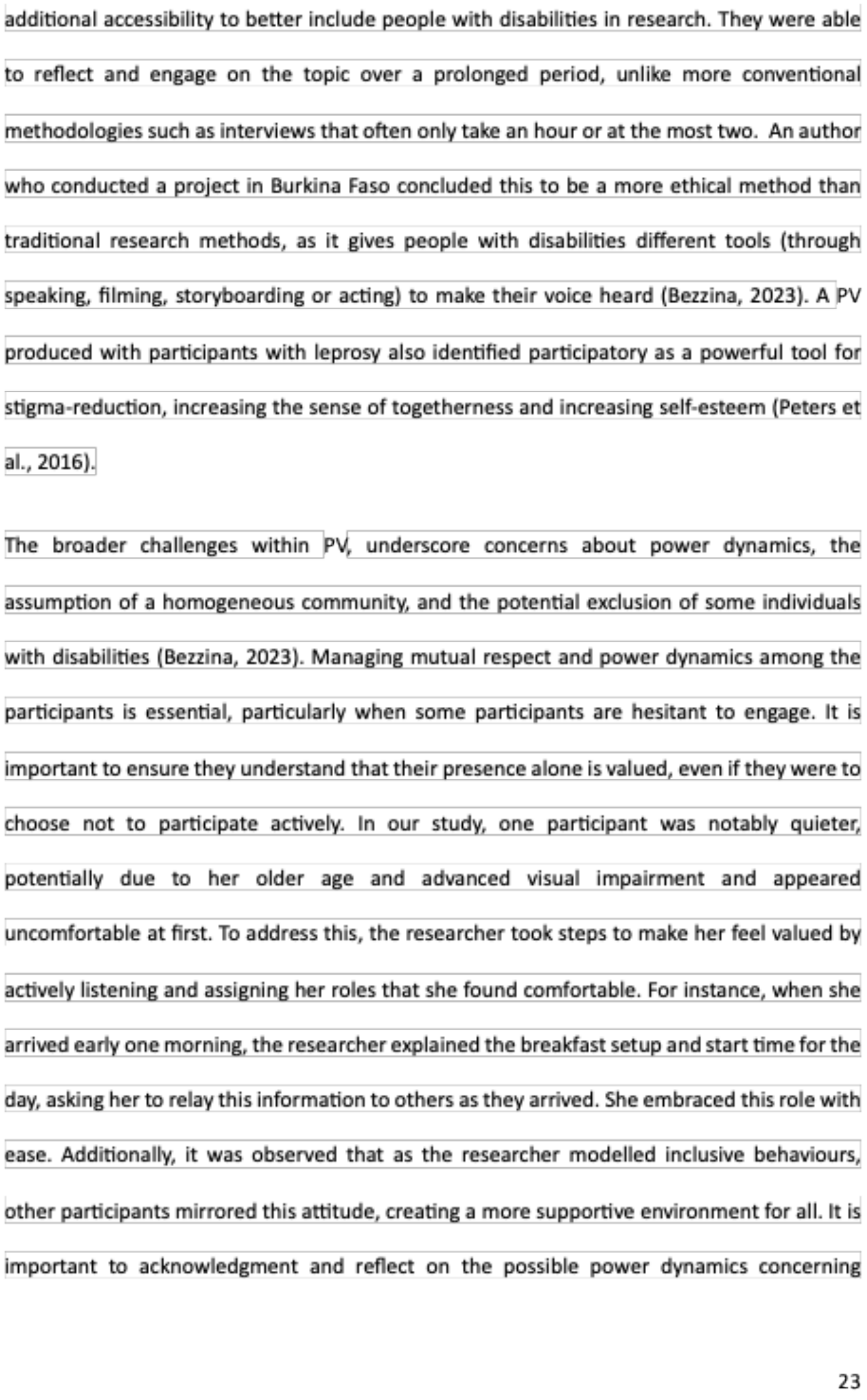
Within the study in Brazil, the PV process involved all participants actively in creating content, such as filming, interviewing, and storyboarding. This hands-on experience was pivotal for fostering a sense of involvement and ownership among participants. Peters et al., (2016) who employed a PV process with people affected by leprosy, emphasised the transformative



potential of PV. Participants in Peters' study, who had never imagined themselves producing media content, expressed a newfound sense of pride and accomplishment: “people like me do not make things like that”. Similarly, caregivers and family members witnessed a positive impact on participants, like Tancleide, who felt proud seeing her son actively participating in the filmmaking process. These observations highlight the potential empowering nature of the PV process. By enabling participants to take an active role in the creation of content, PV challenges preconceived notions of capability and contribution among marginalized groups. It not only provides a platform for expressing individual and collective experiences but also fosters a sense of achievement and visibility for participants who are often sidelined. Through PV, research becomes a collaborative and inclusive endeavour, bridging gaps between researchers and participants and enriching the research outcomes with diverse perspectives and voices.

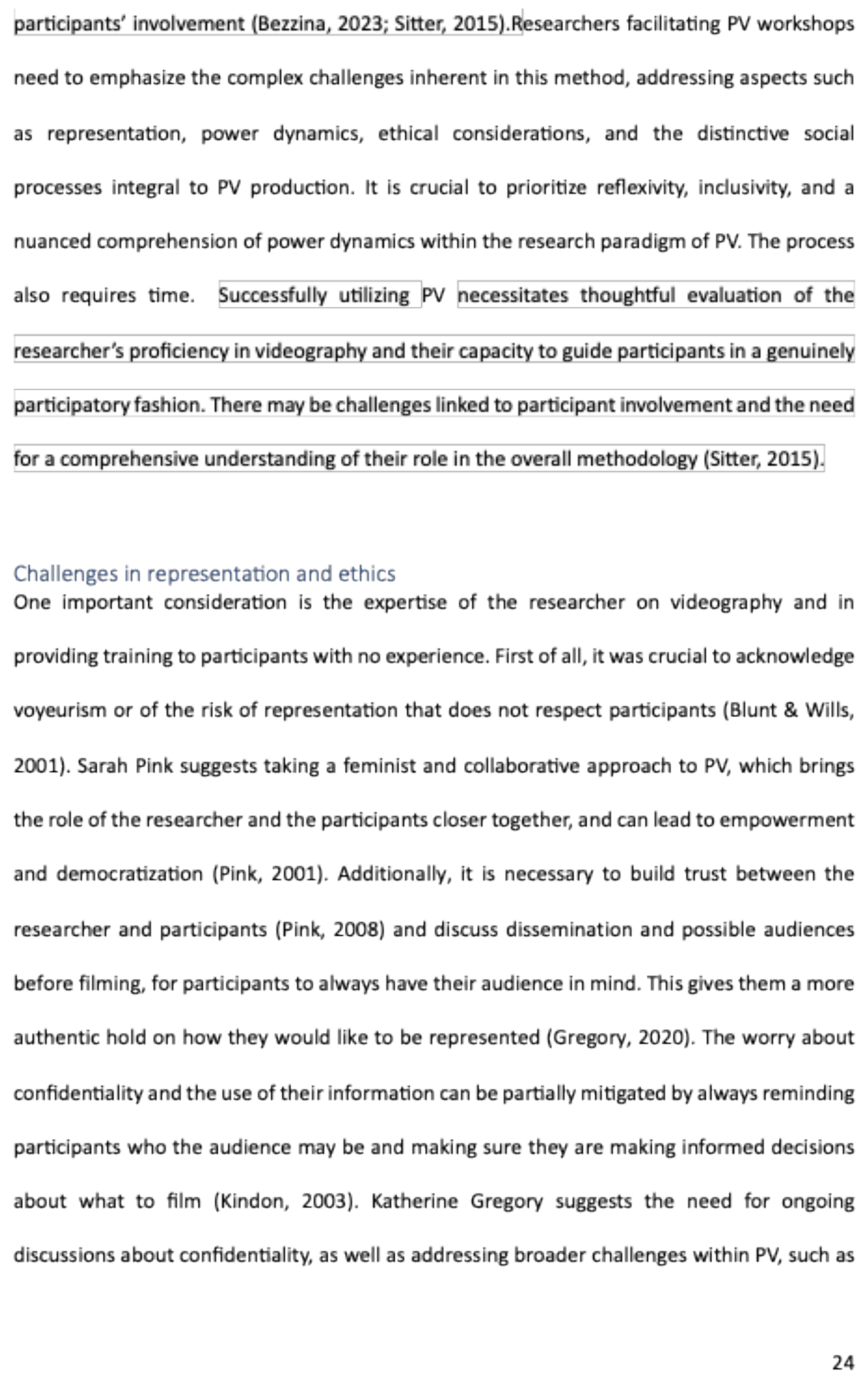
The advantage of this method is that participants can relate to the product that is produced. Participants were given the autonomy to share the video as they wish among their local community, which they shared with healthcare professionals and family members. Additionally, they were virtually present during the dissemination event and informed of the final recommendations that were developed because of the findings. This not only supports what McClimens (McClimens, 2008) said about giving credit to authors when sharing research, but it also makes sure that we involve these participants in the dissemination process.

The participants in the study participated more holistically in the PV than the interviews, giving input in different steps of the research process, as co-researchers (Freire, 2005). All participants were involved in one way or another, with the PV process giving space for



additional accessibility to better include people with disabilities in research. They were able to reflect and engage on the topic over a prolonged period, unlike more conventional methodologies such as interviews that often only take an hour or at the most two. An author who conducted a project in Burkina Faso concluded this to be a more ethical method than traditional research methods, as it gives people with disabilities different tools (through speaking, filming, storyboarding or acting) to make their voice heard (Bezzina, 2023). A PV produced with participants with leprosy also identified participatory as a powerful tool for stigma-reduction, increasing the sense of togetherness and increasing self-esteem (Peters et al., 2016).

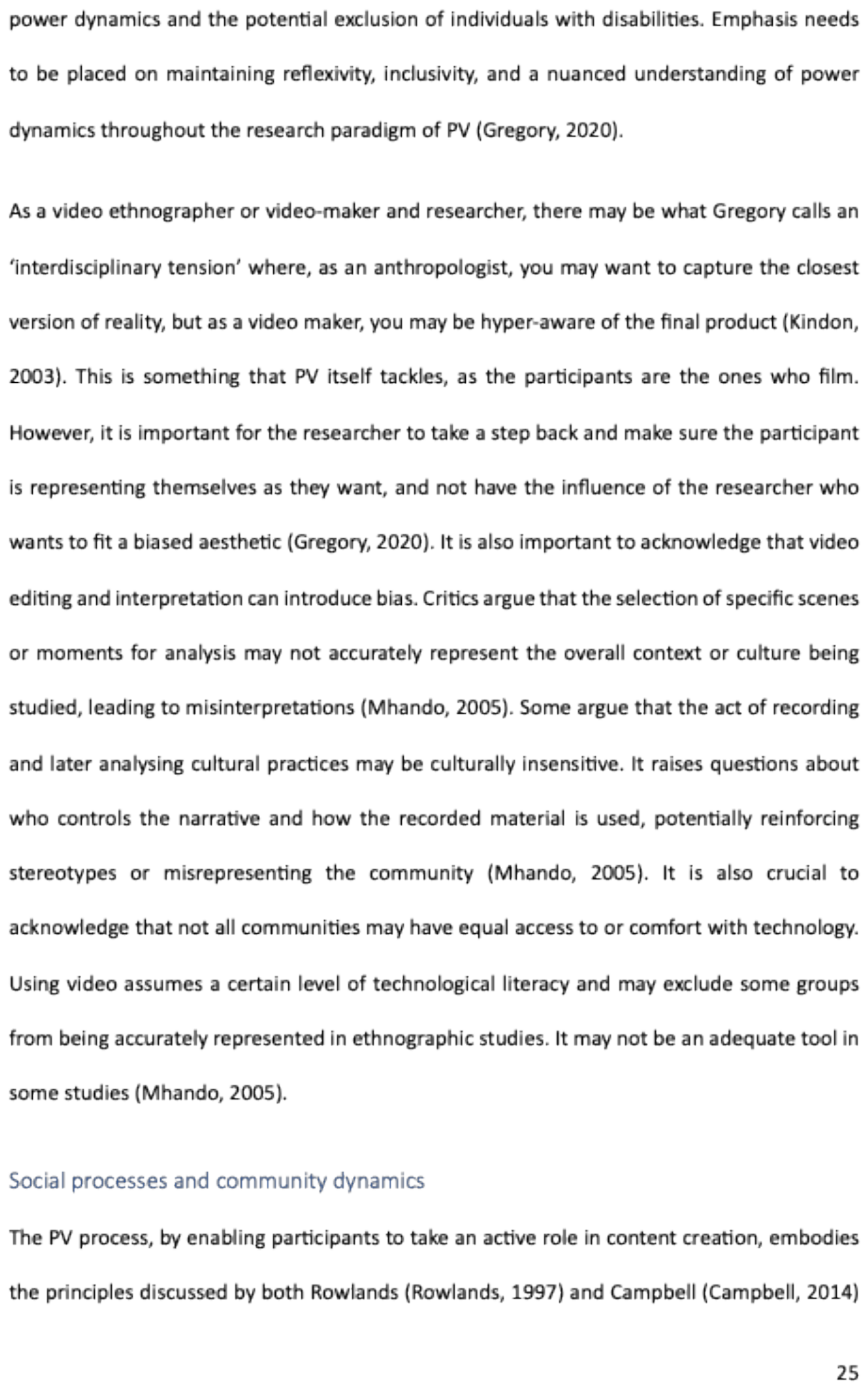
The broader challenges within PV, underscore concerns about power dynamics, the assumption of a homogeneous community, and the potential exclusion of some individuals with disabilities (Bezzina, 2023). Managing mutual respect and power dynamics among the participants is essential, particularly when some participants are hesitant to engage. It is important to ensure they understand that their presence alone is valued, even if they were to choose not to participate actively. In our study, one participant was notably quieter, potentially due to her older age and advanced visual impairment and appeared uncomfortable at first. To address this, the researcher took steps to make her feel valued by actively listening and assigning her roles that she found comfortable. For instance, when she arrived early one morning, the researcher explained the breakfast setup and start time for the day, asking her to relay this information to others as they arrived. She embraced this role with ease. Additionally, it was observed that as the researcher modelled inclusive behaviours, other participants mirrored this attitude, creating a more supportive environment for all. It is important to acknowledgment and reflect on the possible power dynamics concerning



participants' involvement (Bezzina, 2023; Sitter, 2015).Researchers facilitating PV workshops need to emphasize the complex challenges inherent in this method, addressing aspects such as representation, power dynamics, ethical considerations, and the distinctive social processes integral to PV production. It is crucial to prioritize reflexivity, inclusivity, and a nuanced comprehension of power dynamics within the research paradigm of PV. The process also requires time. Successfully utilizing PV necessitates thoughtful evaluation of the researcher's proficiency in videography and their capacity to guide participants in a genuinely participatory fashion. There may be challenges linked to participant involvement and the need for a comprehensive understanding of their role in the overall methodology (Sitter, 2015).

Challenges in representation and ethics

One important consideration is the expertise of the researcher on videography and in providing training to participants with no experience. First of all, it was crucial to acknowledge voyeurism or of the risk of representation that does not respect participants (Blunt & Wills, 2001). Sarah Pink suggests taking a feminist and collaborative approach to PV, which brings the role of the researcher and the participants closer together, and can lead to empowerment and democratization (Pink, 2001). Additionally, it is necessary to build trust between the researcher and participants (Pink, 2008) and discuss dissemination and possible audiences before filming, for participants to always have their audience in mind. This gives them a more authentic hold on how they would like to be represented (Gregory, 2020). The worry about confidentiality and the use of their information can be partially mitigated by always reminding participants who the audience may be and making sure they are making informed decisions about what to film (Kindon, 2003). Katherine Gregory suggests the need for ongoing discussions about confidentiality, as well as addressing broader challenges within PV, such as



power dynamics and the potential exclusion of individuals with disabilities. Emphasis needs to be placed on maintaining reflexivity, inclusivity, and a nuanced understanding of power dynamics throughout the research paradigm of PV (Gregory, 2020).

As a video ethnographer or video-maker and researcher, there may be what Gregory calls an 'interdisciplinary tension' where, as an anthropologist, you may want to capture the closest version of reality, but as a video maker, you may be hyper-aware of the final product (Kindon, 2003). This is something that PV itself tackles, as the participants are the ones who film. However, it is important for the researcher to take a step back and make sure the participant is representing themselves as they want, and not have the influence of the researcher who wants to fit a biased aesthetic (Gregory, 2020). It is also important to acknowledge that video editing and interpretation can introduce bias. Critics argue that the selection of specific scenes or moments for analysis may not accurately represent the overall context or culture being studied, leading to misinterpretations (Mhando, 2005). Some argue that the act of recording and later analysing cultural practices may be culturally insensitive. It raises questions about who controls the narrative and how the recorded material is used, potentially reinforcing stereotypes or misrepresenting the community (Mhando, 2005). It is also crucial to acknowledge that not all communities may have equal access to or comfort with technology. Using video assumes a certain level of technological literacy and may exclude some groups from being accurately represented in ethnographic studies. It may not be an adequate tool in some studies (Mhando, 2005).

Social processes and community dynamics

The PV process, by enabling participants to take an active role in content creation, embodies the principles discussed by both Rowlands (Rowlands, 1997) and Campbell (Campbell, 2014) regarding the distribution and exercise of power. It serves as a practical example of how understanding power dynamics—whether through a materialist lens focusing on societal structures or a social constructionist lens emphasizing fluid, relational power—can inform participatory approaches. PV has the potential to challenge traditional power hierarchies by providing marginalized groups a platform to express their experiences and perspectives, thereby fostering a sense of achievement and visibility for those often side lined. Through the lens of Freire's materialist conception of power, PV can be seen as a tool for "conscientisation," enabling participants to recognise and articulate the structural barriers—such as race, gender, age, or social class—that affect their lives. This recognition empowers participants to contribute to the research process actively, challenging the structures that perpetuate inequality. During our study, throughout the various moments of sharing their stories, discussing access to healthcare, and deciding what to include in the film, participants engaged in a repeated cycle of reflection and learning. This ongoing dialogue not only deepened their understanding of their own lived experiences but also highlighted the common challenges they faced as a collective. As they contemplated how best to represent their experiences on film to policy makers and their other target audiences, they began to critically examine the structural barriers impacting their lives. This iterative process of storytelling, discussion, and decision-making served as a pathway to 'conscientisation,' fostering a sense of empowerment and agency in challenging the inequalities they confronted.

The PV process has the potential to not only bridge gaps between researchers and participants, enriching research outcomes with diverse perspectives and voices, but also acts as a catalyst for rethinking and redistributing power within community participation and societal structures. It highlights the critical role of understanding power dynamics in designing and implementing participatory research methodologies that are truly inclusive and empowering for all involved. The PV process can stimulate what Giddens (Giddens, 1984) calls the 'practical consciousness', which "consists of all the things which actors know tacitly about how to 'go on' in the contexts of social life without being able to give them direct discursive expression." As opposed to 'discursive consciousness' which "refers to what agents are able to say, both to themselves and to others, about their own action."

Howarth (Howarth, 2006) proposed that through engaging in dialogue, debate, and critique, members of a stigmatized group can gain awareness of their roles as active participants rather than passive subjects. She emphasised that alone the individual cannot develop the confidence and emotional strength to challenge stigma but can do so in combination with others (Buchanan & Murray, 2012). Participants reported this as part of the PV workshop conducted in Colombia, where participants became aware of their need being a collective need and not just individual. It was meaningful and empowering to them to hear others who go through similar barriers (Reichenberger et al., 2022). Other PV projects have been shown to have a similar social impact, where the process facilitates the shift in dynamics between people within a community. As mentioned by Chris High et al "Although making a film good enough to show others was a common goal, the social process of making the film and the benefits that came from it in terms of learning and improving relationships were experienced as far more important." (High et al., 2012).

Conclusion

In this paper a participatory video (PV) process among adults with disabilities in Arcoverde is described in detail. Participants actively engaged in filming, interviewing, or storyboarding. The process heightened participants' collective awareness, fostering empowerment through shared barriers. Facilitator reflections emphasize the importance of adapting to participants' needs, promoting inclusivity, and addressing potential biases in video production.

The study suggests that participatory visual methods can play an important role in disability research as the PV approach highlight the holistic involvement of participants, positioning them as co-researchers. The PV process has the potential to provides individuals with disabilities diverse tools for self-expression. The researchers' reflections underscore considerations such as expertise, voyeuristic risks, and interdisciplinary tensions. The discussion emphasizes ongoing dialogues, reflexivity, and ethical considerations throughout the research process, addressing challenges related to power dynamics, community assumptions, and potential exclusion of individuals with disabilities. Overall, the paper advocates for a nuanced understanding of power dynamics, prioritizing reflexivity, inclusivity, and ethical awareness in PV research. The methodology has potential – but like all research methods needs funds, resources and time.

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Supporting information [see Appendix 4]

Information sheet and first consent form (Portuguese)

Second consent form (Portuguese)

Chapter 7 Discussion

There is growing evidence that people with disabilities face a range of barriers to healthcare, leading to worse outcome and higher mortality [13]. Qualitative studies allow for deeper exploration of barriers [108], however, generally use in-depth interviews or focus group discussions, which are not fully participatory. In this study, I focussed on measuring the barriers to accessing healthcare for people with disabilities and tested new visual approaches to make this investigation more participatory. First, I undertook a systematic review of the qualitative studies from Latin America and the Caribbean to understand the scope of the literature and the approaches used for qualitative data collection in this context. Next, I undertook traditional in-depth interviews with people with disabilities in Brazil to identify key barriers. I then tested two new approaches using visual methods in Colombia and Brazil, which are more participatory: Digital Storytelling and Participatory Video. I then applied the Participatory Video approach working with people with disabilities in Brazil, and considered the feasibility of the approach and what it showed about barriers to healthcare. The inclusion of studies from Latin America and the Caribbean (Paper 1) and the case study with caregivers of children with CZS in Colombia (Paper 3) was central to the overall aim of this thesis. By exploring healthcare access in various contexts across the region and testing different participatory visual methods, this research offers a comprehensive understanding of the challenges faced by people with disabilities in accessing healthcare. These findings are key to identifying both common patterns and unique factors influencing healthcare access, thereby guiding more effective strategies for improving healthcare services in Brazil and enhancing the research methodologies.

7.1 Summary of findings and implications for policy

7.1.1 Data from Objectives 1 and 2

The qualitative systematic review on healthcare access among adults with disabilities in Latin America and the Caribbean, as well as the in-depth qualitative data collection in Brazil showed that people with disabilities face barriers to access healthcare across different stages of the healthcare seeking journey. These barriers were experienced both from the demand and the supply side, as conceptualized by Levesque et al [92]. As the Levesque framework is not a framework used particularly to look at healthcare access for people with disabilities, some interpretations were made to fit the framework and support analysis and presentation of findings. For example, lack of accessible information was added to ‘ability to perceive’ as without information, people will not be able to have ‘health literacy’ and ‘knowledge about health’. The findings from the systematic review were reinforced through the interviews with people with disabilities in Brazil, which highlighted the barriers experienced when accessing healthcare. The findings from the systematic review and the in-depth interviewers show that the core ‘dimensions’ and ‘abilities’ identified as barriers were ‘ability to perceive’, ‘availability and accommodation’, ‘ability to reach’, ‘appropriateness’ and ‘ability to engage’. Affordability barriers, which are common in other settings, appeared less prominent due to universal healthcare coverage in the studied regions, although medication costs and out-of-pocket expenses were reported challenges for some participants.

The in-depth interviews in Brazil found that participants are generally aware of their treatment needs – supporting the ‘ability to perceive’ need. However, there is a lack of accessible healthcare information and education campaigns, particularly reported by those with visual or hearing impairments, which reduces the ability to perceive healthcare needs. For instance, information is often available in text form, making it inaccessible to people with visual impairments. Particular gaps were identified in information related to sexual health, cancer prevention, and oral hygiene. Knowledge of healthcare options vary, with negative experiences reported, including long waits and short consultations. Communication challenges, particularly reported by those with hearing or visual impairments, hinder ‘ability to engage’. Interviewees highlighted the need for healthcare providers to communicate important information clearly and responsibly. The National Health Policy for Persons with Disabilities places emphasis on providing training for healthcare access to individuals with disabilities, including to improve communication, yet users often experience a contrasting reality [109]. Emphasizing effective communication is crucial for healthcare professionals to deliver care that is both appropriate and humanized [110].

Urban environment poses challenges for ‘ability to reach’, with surrounding areas of healthcare facilities contributing to barriers. These findings are consistent with other studies in Latin America, specifically in Brazil, that showed that inadequate urban infrastructure, such as uneven sidewalks, potholes and obstacles posed a challenge to people reaching healthcare centres [26, 51, 111, 112]. Transportation difficulties, including negative attitudes from drivers, lack of accessible transportation and long distances also impact ability to reach care.

Research conducted in Bahia yielded comparable results, emphasizing the significance of dependable transportation in ensuring continued patient follow-up, particularly in instances where health centre vehicles were not accessible [113]. The importance of transportation barriers were also highlighted in a previous review from Latin America [29]. Furthermore, surrounding areas are often inaccessible, due to issues such as uneven pavements, similar to finding from other Brazilian studies that have underscored accessibility problems [111, 112].

Limited accessibility to healthcare facilities was also identified as an issue affecting ‘availability and accommodation’ and ‘appropriateness’. Healthcare facility accessibility issues include lack of ramps, and inaccessible rooms were identified as barriers throughout this study. Equipment accessibility issues were also reported by participants and some participants cannot undergo necessary examinations. These findings align with earlier reviews, which pinpointed critical concerns related to the insufficient accessibility of primary healthcare, as exemplified by the absence of ramps [29]. This observation is further substantiated by quantitative studies that assessed healthcare facilities in the region [114, 115]. One study showed that certain participants faced difficulty accessing exams that were conducted on inaccessible floors [111]. Girondi et al.'s research emphasized architectural and layout challenges as significant barriers to healthcare accessibility [116], while Santos et al.'s analysis of National Census data on Basic Health Units brought to light nationwide concerns regarding architectural and communication barriers in primary care [117]. Community healthcare agents play a crucial role in enhancing access, but their availability remains restricted, contradicting the objectives outlined in the Política Nacional de Atenção Básica (National Primary Care Policy) [118]. The lack of sufficient funding significantly contributes to the inadequate delivery of primary care services in local communities. This aligns with prior research that identified low rates of home visits, particularly for individuals with chronic health conditions or physical impairments [119]. Home visits are considered valuable, but many participants expressed a need for more support in this regard.

These concerns can be multi-faceted and interconnected. For instance, it was recognized that healthcare providers lack experience in caring for individuals with disabilities, indicating a widespread need for more training. Lack of skills and knowledge of healthcare workers affected the ‘availability and accommodation’, ‘appropriateness’ and ‘ability to engage’ aspects of the Levesque model. This observation corresponds with prior research findings, underscoring the insufficient training healthcare professionals often receive in providing care for individuals with disabilities, encompassing conditions such as spinal cord injuries and Down Syndrome [120, 121]. Attitudinal barriers, stigma, and misdiagnosis identified, impacting the 'appropriateness' and quality of care. Similarly, family and social support play a crucial role in both overcoming barriers to transportation ('ability to reach') and engagement with healthcare services ('ability to engage'). This corresponds with earlier research conducted in Brazil, underscoring the crucial involvement of family members or caregivers in the healthcare journeys of individuals with disabilities. These individuals play essential roles in seeking care, facilitating access, communicating with healthcare professionals, and improving treatment outcomes [122, 123]. Our analysis aligns with two prior reviews in recognizing an overarching unfulfilled demand for healthcare provider training, stemming from reported deficiencies in knowledge, skills, and communication hurdles, and how this gap leads to a greater need for social and family support [29, 124]. Moreover, the importance of family and social support in overcoming transportation and facility accessibility challenges was highlighted in our interviews.

Our study in Brazil provides insights into participants' knowledge of healthcare options, reporting negative experiences such as long waits and short consultations. It also addresses challenges related to medication costs and out-of-pocket expenses. Additionally, we found throughout study that there is an issue around equipment accessibility, with some participants unable to undergo necessary examinations due to these challenges. The value of home visits to overcome barriers was also very present in our study.

The Levesque framework proved to be a valuable framework in facilitating the analysis of research findings, providing a solid foundation for examining various aspects of healthcare access. However, it became evident that the framework lacked specificity in addressing disability-related issues. To address this limitation, additional categories were incorporated to capture the unique challenges faced by individuals with disabilities. The adaptation required a thoughtful consideration of disability-related barriers, ensuring that the modified framework remained inclusive and comprehensive in its approach to healthcare access. Despite the need for adjustments, the Levesque framework served as a beneficial starting point, highlighting the importance of tailoring existing models to encompass the specific nuances associated with disability-related healthcare challenges.

7.1.2 Implications for Brazilian policies and international commitments

Implications for international commitments

Analysing these findings through the lens of the Convention on the Rights of Persons with Disabilities (UNCRPD), it is evident that several rights of persons with disabilities are being compromised in the context of healthcare in Brazil.

When looking at the Right to Health (Article 25) [11], participants with disabilities face challenges in communication and access to health information, compromising their right to health. Negative experiences, long waits, and short consultations contribute to barriers in accessing timely and appropriate healthcare. Regarding Article 9, on accessibility, transportation barriers, uneven pavements, and inaccessible surrounding areas highlight a lack of accessibility in the physical environment, violating the right of persons with disabilities to access healthcare facilities on an equal basis with others. Our study reveals that participants encounter communication difficulties in healthcare settings, preventing them from exercising their right to freedom of expression and opinion, and access to information (Article 21). Lack of training for healthcare providers in disability care further restricts the active participation of individuals with disabilities in their healthcare decisions. Attitudinal barriers, stigma, and misdiagnosis reported by participants indicate discriminatory practices within the healthcare system, infringing upon the principle of non-discrimination outlined in Article 5 of the UNCRPD. The findings suggest a lack of training and awareness among healthcare providers, impacting the quality of care for persons with disabilities. Participants face challenges in accessing health information due to poor healthcare literacy, highlighting a violation of the right to accessible information for persons with disabilities (Article 21). Medication costs and out-of-pocket expenses pose challenges for participants, indicating potential violations of the right to an adequate standard of living for persons with disabilities

(Article 28). Transportation barriers, especially for those with physical or visual impairments, impede personal mobility and compromise the right to healthcare services (Article 20) [11].

Our study underscores the need for comprehensive measures to align healthcare practices in Brazil with the principles and rights outlined in the Convention on the Rights of Persons with Disabilities, ensuring equal access, non-discrimination, and active participation for individuals with disabilities in the healthcare system. Our findings also highlight that other international commitments are not being met, due to the failure to provide appropriate services for people with disabilities. For instance, the 2023 UN Political Declaration of the High Level Meeting on UHC [125] makes several references to the health inequalities experienced by people with disabilities and the need to ensure that health services are disability-inclusive.

Implications for Brazilian policies

The findings from our qualitative systematic review and in-depth interviews in Brazil reveal crucial policy considerations that resonate with the principles embedded in the Brazilian Law of Inclusion. These insights, if addressed, have the potential to significantly improve healthcare access and outcomes for individuals with disabilities. The National Health Policy for people with disabilities (PNSPCD) in Brazil, that aims to promote the quality of life, inclusion, and prevention of disability faces challenges in achieving universality, integrality, and equity, despite its widespread commitments to inclusive healthcare in Brazil.

A glaring challenge is the absence of accessible healthcare information campaigns. To overcome this barrier, the PNSPCD should formulate specific guidelines and initiatives for disseminating healthcare information in accessible formats, aligning with the law's emphasis on inclusive communication strategies. Transportation barriers, compounded by negative attitudes from drivers and a lack of accessible transportation, directly impede access to care. A collaborative approach between the healthcare sector and transportation authorities, in harmony with the PNSPCD's objectives, could foster the development of accessible transportation options and training programs for drivers. Issues related to uneven pavements, lack of ramps, and inaccessible rooms within healthcare facilities underscore the need for enhanced physical infrastructure. The PNSPCD could play a pivotal role by incorporating guidelines to ensure universal accessibility in healthcare facilities, endorsing the use of assistive devices to enrich the overall healthcare experience.

The deficiencies identified in healthcare provider training on disability care emphasize the urgent need for increased awareness, sensitivity, and proficiency. The PNSPCD's focus on human resource training aligns well with the recommendation for comprehensive training programs, offering a pathway to significantly elevate the quality of care for individuals with disabilities. Recognizing the diverse challenges across different regions, policy interventions should be tailored to address specific regional needs and disparities. This nuanced approach can enhance the overall effectiveness of the PNSPCD in promoting inclusive healthcare practices nationwide. The value placed on home visits as a means to overcome barriers is evident from our research, with participants expressing a need for additional support. Acknowledging the significance of home visits, the PNSPCD could consider provisions that actively promote and support home-based healthcare services. Equipment accessibility challenges present a hindrance to individuals undergoing necessary examinations. Policies addressing these challenges, ensuring universal availability, can contribute substantially to creating a more inclusive healthcare system. Communication challenges impede effective engagement. The PNSPCD could underscore the development of clear communication guidelines for healthcare providers, ensuring that important information is conveyed responsibly and comprehensively. Participants reported challenges related to knowledge of healthcare options, long waits, and short consultations, emphasizing the need for policies that enhance the accessibility of healthcare options, reduce waiting times, and extend consultation durations. Such policies can contribute to fostering a more patient-centric approach.

Aligning policy interventions with these identified implications holds the promise of cultivating a more inclusive and accessible healthcare system in Brazil, staying true to the foundational principles of the Brazilian Law of Inclusion.

7.1.3 Implications for health service delivery and achievement of UHC in Latin America and the Caribbean

The findings from the research have significant implications for health service delivery and the pursuit of universal health coverage (UHC) in the region of Latin America and the Caribbean, but specifically, in Brazil. The identified gaps in accessible healthcare information and education campaigns, highlight a critical need for policy interventions. To achieve UHC, policies must address the accessibility of information, ensuring it is available in formats suitable for diverse impairments. Transportation barriers emerged as a consistent theme impacting healthcare access. Initiatives should focus on improving transportation infrastructure, fostering inclusive practices, and promoting positive attitudes toward individuals with disabilities through training support. Additionally, our findings emphasize the crucial role of family and social support in overcoming transportation challenges, suggesting the need for policies or strategies that recognize and support these informal networks.

Healthcare facility accessibility issues, such as uneven pavements, lack of ramps, and inaccessible rooms, highlight the importance of incorporating universal design principles into healthcare infrastructure. Policies should mandate and incentivize healthcare facilities to ensure physical accessibility, promoting an inclusive environment for all individuals. Furthermore, addressing training deficiencies among healthcare providers regarding disability care is crucial. Policy interventions should prioritize ongoing training programs to enhance healthcare professionals' knowledge and sensitivity to the needs of individuals with disabilities. Our findings also underscore the impact of attitudinal barriers, stigma, and misdiagnosis on the quality of care. Activities promoting awareness, education, and cultural competence training for healthcare providers can contribute to fostering a more inclusive healthcare environment. Communication challenges identified in both the systematic review and the in-depth interviews emphasize the need for policies that mandate clear communication practices in healthcare settings.

While the systematic review identified a lack of accessible healthcare campaigns, the in-depth interviews in Brazil provided additional insights into regional differences and specific challenges faced by individuals in different states. These regional nuances underscore the importance of tailoring policies to address local contexts and needs. Additionally, the study in Brazil introduced themes such as health options and experiences, equipment accessibility, and the value of home visits. Policies should consider these unique aspects to ensure comprehensive and inclusive healthcare services.

The implications of these findings for policy and UHC in Latin America and the Caribbean are therefore extensive. Addressing the identified gaps in information accessibility, transportation, healthcare facility infrastructure, healthcare provider training, and attitudinal barriers requires a multifaceted and targeted policy and programme approach. By incorporating these insights into policy design and programme implementation, governments can work towards achieving UHC that is truly inclusive and equitable for individuals with disabilities in the region. Indeed, Hannah Kuper and Johanna Hanefeld argue that achieving UHC without addressing the needs of people with disabilities is not feasible [4]. Their suggested approach involves a twin-track strategy: integrating people with disabilities into mainstream health services while also providing specific services tailored to their needs, such as rehabilitation and assistive devices. They conclude that focusing on people with disabilities when developing UHC strategies will not only benefit people with disabilities but also contribute to overall health system responsiveness, diversity, and equity. They recommend improving healthcare centre accessibility, strengthening linkages between sectors, and providing more training for healthcare professionals.

7.2 Implications for research on access to healthcare for people with disabilities in LAC

The systematic review primarily included studies conducted in Brazil, highlighting a gap in qualitative data from other Latin American and Caribbean countries on healthcare access for adults with disabilities. This indicates a limited understanding of healthcare access among adults with disabilities in the broader regional context. The emphasis on Brazil in previous studies underscores the need for broader geographical representation to create a comprehensive regional understanding. Researchers should strive to extend qualitative investigations beyond Brazil, encompassing diverse countries in the Latin American and Caribbean region. This expansion would not only enhance the generalizability of findings but also contribute to a more nuanced understanding of the unique challenges and facilitators impacting healthcare access in different cultural and contextual settings.

Furthermore, future research endeavours should prioritize cross-regional data collection to enable meaningful comparisons and identify patterns that transcend local contexts. This approach will facilitate the identification of best practices, and the development of targeted interventions tailored to the specific needs of different regions. Collaborative efforts involving multiple countries can lead to a more robust evidence base, allowing policymakers and healthcare practitioners to implement effective strategies that address the commonalities and distinctions in healthcare access challenges across Latin America and the Caribbean.

Moreover, the absence of studies gathering data from various regions for cross-regional comparisons is a notable gap identified in the systematic review. Existing research concentrated on single cities, hindering a nationwide perspective. The lack of cross-regional data prevents a nuanced analysis of variations and similarities in healthcare access, limiting the potential for identifying best practices or tailored local policies. In response to this gap, my Ph.D. research unusually encompasses different regions in Brazil.

7.3 Implications for use of participatory visual methods to explore access to healthcare for people with disabilities in LAC

Currently, there is limited participation, as well as participatory visual methodologies, in research related to disabilities. This gap is particularly noticeable in low- and middle-income countries (LMICs), where obstacles like insufficient funding, a shortage of trained disabled researchers, and accessibility challenges are potentially exacerbated, with some exceptions [126-128]. For example, a recent review focusing on the use of photovoice to capture the experiences of individuals with physical disabilities found 20 papers, of which only three included data from LMICs [62], of which none were conducted in Latin America and the Caribbean.

When participation does take place, it frequently revolves around seeking input on research methods and outcomes, making it somewhat superficial in nature [95]. This situation might stem from practical factors, such as the necessity to plan and fund accommodations for disabled researchers or the limited number of disabled researchers available. Nevertheless, the main underlying cause is probably a lack of awareness concerning the significance of participatory approaches and the actions that should be taken. Consequently, disability research misses out on the valuable reservoir of experience and knowledge possessed by individuals with disabilities, which could potentially lead to ill-informed policies and programs [129].

Recognizing these challenges, this research sought to address these gaps by incorporating participatory visual methods. By leveraging visual methodologies, we aimed to enhance the depth and authenticity of participant engagement and ensure a more comprehensive representation of the experiences of people with disabilities.

For the case study conducted in Colombia, one Participatory Video (PV) and four Digital Stories (DST) were created. The PV focused on evaluating the Juntos programme, while DST focused on healthcare access. Eight caregivers participated in PV; four completed DST and in-depth interviews. Of the main outcomes, caregivers mentioned the use of camera and videography skills being a new skill they learned during the PV process. DST revealed one participant's passion for writing and future plans for a book. Participants collectively portrayed common themes in PV and appreciated the collective work and community building experience. The editing process reflected a sense of unity and empowerment. There was space for caregivers to learn from each other, enhancing community bonds. Caregivers reported feeling appreciated and having control over their ideas. PVM (Participatory Video Methods) empowered caregivers, creating a space for critical reflection. There was an importance given to dialogue, being heard, and self-perception in empowerment. The facilitator played a crucial role in explaining and adapting the process. The experience highlighted the need for an intimate, non-hierarchical relationship for effective participation. This study suggests that PVM is not only feasible but also empowering for caregivers, fostering community, and enhancing self-perception. The facilitator's role, transparent communication, and an intimate relationship were crucial in the success of the participatory process.

The Participatory Video (PV) process in Brazil explores the process of PV, emphasizing the different stages such as welcoming, story circles, video making, storyboarding, editing, ethical considerations, dissemination, and facilitator reflection. During the welcoming stage, the facilitator focused on creating a collaborative environment, challenging traditional research dynamics. The story circle sessions allowed participants to share personal experiences, leading to a broader reflection on healthcare and disabilities. Video making involved using digital technologies as multisensorial tools to engage participants, with an emphasis on mitigating the "observer effect" and building trust [130]. Storyboarding involved a collective effort to determine the video's content, with a shift towards rehabilitation from primary healthcare. The editing process, primarily led by the facilitator, aimed to involve participants in reviewing and providing feedback on the footage. Ethical considerations ensured participants' informed consent, privacy, and awareness of potential audiences. The dissemination process involved showcasing the video to healthcare professionals, family members, and in university settings. An event in Brasilia facilitated discussions among stakeholders, highlighting the challenges faced by people with disabilities. The video served as a catalyst for change, influencing recommendations for more inclusive healthcare provision. The facilitator's reflection acknowledges the cons of using video, including the need for extensive training, potential self-awareness of the camera, and concerns about confidentiality. The study also raises awareness of video editing introducing bias and potential cultural insensitivity [90, 131]. The facilitator reflects on the interdisciplinary tension between capturing reality and creating a visually appealing final product. Lastly, the study acknowledges that not all communities may have equal access to or comfort with technology, posing a limitation in some ethnographic studies [131].

Future studies may consider adopting participatory visual methods. In the experience of the studies in Brazil and Colombia, incorporating participatory visual methods not only enriches the depth of understanding but also empowers individuals with disabilities to actively contribute to the research process. As researchers continue to explore novel methodologies to engage people with disabilities and extend their focus beyond individual cities, the collective body of knowledge on healthcare access for adults with disabilities in the region can advance, ultimately fostering more inclusive and effective healthcare policies and practices.

7.3.3 Reflection on qualitative methods in global disability research

In the realm of disability research, the utilization of in-depth interviews and participatory visual methods (PVM) brings forth a dynamic interplay, each approach offering unique advantages and considerations. While my experience did not involve a direct comparison of the two methods, I am inclined to believe that employing both a PVM and another more established research method in academia could present a comprehensive and inclusive research strategy. It became evident that some participants were hesitant to engage, and relying solely on PVM might inadvertently exclude individuals averse to video participation due to privacy concerns, time constraints, or confidentiality anxieties. This dual-method approach caters to a broader range of preferences, ensuring a more representative and diverse participant pool.

However, a nuanced analysis goes beyond merely comparing the data yielded by each method. The comparison should extend to the social impact and dissemination strategies employed, acknowledging that the strengths of each method lie in different dimensions. It is crucial to recognize that my goal is not to establish a hierarchy between the two, but to harness their complementary strengths. This approach respects the diversity of participant preferences and optimizes the richness of the insights gathered, enhancing the overall quality of the research. In navigating the landscape of disability research methodologies, acknowledging the strengths and limitations of both in-depth interviews and PVM is essential. The choice between these methods should align with the research objectives, ensuring inclusivity, authenticity, and a holistic understanding of the experiences of individuals with disabilities. The synergy of these approaches contributes to a more nuanced and socially impactful exploration of disability-related topics.

When considering in-depth interviews and focus group discussions within the Participation Ladder, they fall quite low in the rungs. They typically fall closer to the lower rungs of the ladder. They often fall under 4 and 5, where they are assigned and informed, or at best consulted and informed about the research process. While they provide an opportunity for individuals to express their opinions, the decision-makers may or may not integrate this input into the final decision. Participatory video falls higher on the rungs of the participation ladder. PV inherently involves collaboration between researchers or facilitators and community members. The process is a joint effort where both parties contribute to decision-making, shaping the narrative, and determining the focus of the video. In PV, participants often take on various roles in the video-making process, from conceptualization to filming to editing. This delegation of power allows community members to actively shape the representation of their experiences. When implemented with a genuine commitment to shared decision-making, it can contribute to a more equitable and participatory research process.

While the participation ladder is a valuable framework, its hierarchical nature suggests that the ideal approach is emancipatory research, where individuals with disabilities take full control of the study [97]. According to Danieli and Woodhams [93], proponents of emancipatory research argue that any other method "perpetuates the oppression of disabled people" [93]. This perspective, referred to as the "right on" approach by Holland et al. [132], assumes that emancipatory research yields more ethical results, making it challenging to evaluate participatory approaches (pp.1-2). However, the ladder fails to acknowledge the potentially significant role that non-disabled researchers can play in such studies.

Despite my background in Visual Anthropology and over eight years of experience as an ethnographic filmmaker, I am not disabled myself. Nonetheless, I have knowledge and skills applicable to qualitative research. It is essential, as emphasized by Nind [133], to comprehend the motivations of researchers engaging in participatory research. In this PhD study, my commitment to inclusive research, aligned with the principle of 'nothing about us without us' [134], drove the choice of participatory approaches. Nevertheless, as explained by Conolly [135], participatory approaches and methods can intertwine political and practical motivations. This aligns with my observations, as I discovered that participatory methods are more accessible and foster co-produced research [133].

7.3.4 Use of participatory video in global disability research

In the context of disability studies, the exploration of the moving image can open new avenues for understanding the experiences of individuals with disabilities. Participatory visual methods can serve as a powerful tool for capturing and conveying the diverse narratives of people with disabilities, providing insights into their daily lives, challenges, and triumphs.

Paulo Freire, a renowned Brazilian educator and philosopher, is best known for his influential theory of participatory education. Central to Freire's theory is the idea that education should be a liberating and transformative process that empowers individuals and promotes social justice [77]. His principles of participation can be applied to various fields, including disability studies, where participatory research methods can help challenge dominant narratives, empower marginalised voices, and foster inclusive practices. In Freire's view, participation is not simply about involving individuals in decision-making processes; it is a fundamental aspect of human agency and democratic practice. He emphasizes the importance of dialogue and reciprocal learning, where researchers and participants engage in a horizontal relationship based on mutual respect and collaboration. This approach stands in contrast to traditional research models that often position researchers as experts and subjects as passive recipients of knowledge.

When applying Freire's theory to participatory visual research in disability studies, several key elements emerge. Firstly, the research process should actively involve individuals with disabilities as co-researchers, recognising their expertise and lived experiences. This inclusion promotes a more nuanced understanding of disability and challenges the prevailing medical or deficit-based models. By centring the voices of people with disabilities, participatory visual research can address their unique needs, concerns, and aspirations. Additionally, Freire's theory advocates for a dialogical approach, emphasizing the importance of should not be confined to academic inquiry alone but should aim to create practical and positive changes in the lives of individuals with disabilities. This may involve advocating for policy changes, influencing community practices, or developing inclusive interventions based on the research findings.

It is important to reflect on the possible challenges when using participatory video. Participatory video analysis is currently still understudied and points to challenges in relation to how participants are involved in the analysis of the films and the process [90]. Participatory editing is also challenging, as it requires time, balancing choices and making sure to represent voices that are overlooked [90]. Further exploration and discussion is needed on this. The use of participatory video sometimes assumes a homogenous community with similar experiences, but how do you represent different voices and experiences within a video [91]. There is a risk of excluding individuals with certain disabilities, such as severe intellectual and hearing impairments, which can present challenges in facilitating the participatory process [91]. Reflexivity is constantly important, although the power imbalances remains [91].

The production of scientific evidence regarding disability hinges on research practices that align with Article 3, Clause 3 of the UNCRPD, emphasizing the imperative of ensuring the "full and effective participation and inclusion of disabled people." This resonates with a fundamental tenet of the Disability Rights Movement encapsulated in the principle of "Nothing about us, without us." This principle underscores the critical need for genuinely incorporating disabled individuals in endeavours that directly impact them [63], and this may be supported through the use of participatory visual methods with people with disabilities. These methods foster a more inclusive and empowering research environment. By allowing individuals with disabilities to actively contribute to the creation of visual representations, researchers provide a platform for self-expression, enabling participants to communicate their unique perspectives beyond the limitations of verbal communication. This inclusive approach not only respects the principle of "Nothing about us, without us" but also ensures that the research findings more accurately reflect the diverse experiences within the disabled community.

Participatory visual methods enhance the richness and depth of data gathered. The audio visual can convey nuanced emotions, contextual details, and non-verbal cues that might be challenging to capture through traditional interview methods. For individuals with certain communication barriers or intellectual disabilities, visual methods offer an alternative means of expression, allowing them to convey their thoughts and experiences in a way that aligns with their unique communication styles. This not only contributes to a more comprehensive understanding of their lived experiences but also broadens the scope of the research, making it more inclusive and representative of the diverse array of disabilities and individual differences within the community.

7.4 Strength and limitations of the PhD

The systematic review examined an unexplored theme, pioneering a comprehensive examination of healthcare access among adults with disabilities in Latin America and the Caribbean. This unique contribution significantly expands the existing literature on the subject. The study in Brazil further advanced this pioneering spirit, breaking new ground by conducting a comparative analysis across four distinct locations within the country. This approach marked a departure from the conventional single-location studies, providing a more nuanced understanding of regional variations in healthcare access.

As a Brazilian national with fluency in Portuguese, coupled with specialized training in visual anthropology and participatory video techniques, I brought a unique set of skills and perspectives to the research. The use of participatory video in academia within the Latin America and the Caribbean context to explore healthcare access among adults with disabilities marked a notable milestone. This innovative methodology facilitated a more immersive and participant-centred approach.

However, it is essential to acknowledge certain limitations in the study. The research primarily focused on public health and the SUS, potentially overlooking the intricacies of the relationships between public and private healthcare sectors. Additionally, the study unfolded amid the challenging backdrop of the COVID-19 pandemic, impacting the ability to conduct face-to-face interviews and build rapport with participants. This limitation constrained the comparative analysis between data gathered through in-depth interviews and participatory video sessions.

Additionally, a critical aspect examined in the research focused on the dynamics of engagement in the participatory video process. Notably, a considerable number of potential participants opted not to partake, and the reasons behind their decisions remain undisclosed. The factors influencing their choice could range from concerns about the time commitment required for the workshop, apprehensions related to the ongoing COVID-19 pandemic, or reservations regarding the lack of anonymity associated with video participation. This uncertainty poses a limitation to the study, as a deeper understanding of these motivations could offer valuable insights for shaping future research endeavours.

7.5 Conclusion

In conclusion, the active involvement of people with disabilities is fundamental to the essence of the Disability Movement, embodying the slogan "Nothing About Us, Without Us." Qualitative research continues to show that people with disabilities face barriers in their healthcare seeking journey that need to be addressed through programme and policy change. While the imperative to address these challenges is clear, it is equally crucial to ensure that the voices of people with disabilities are not just considered but play a central role in shaping these transformative efforts. Regrettably, the data collected for exploring these issues often lacks a participatory dimension.

Integrating participatory visual methods into research practices offers innovative avenues to co-produce with people with disabilities in the exploration of healthcare-related issues. This approach facilitates a more inclusive and collaborative process, ensuring that the experiences, perspectives, and needs of people with disabilities are accurately represented. As we strive for continuous improvement in the realm of public health, it is imperative to adhere to the principle of "Leave No One Behind," emphasizing inclusivity and the active participation of all individuals, including those with disabilities, in the ongoing efforts to advance health equity and accessibility.

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Appendix

Appendix 1. Supporting information for Paper One

Search Terms

Ovid

#	Searches	Annotations
1	(Caribbean or Latin America or Central America or South America).ti,ab.	
2	exp caribbean region/ or exp central america/ or latin america/ or exp south america/	
3	(Guadaloupe or Aruba or Martinique or Turks or Caicos or Turks and caicos islands or virgin islands or Peru or Argentina or Brazil or Chile or Colombia or Venezuela or Cayman Or Puerto Rico Or Saint Barthelemy or ST Barthelemy or Guatemala or Ecuador or Bolivia or Haiti or Cuba or Dominican Republic or Honduras or Paraguay or Nicaragua or El Salvador or Costa Rica or Panama or Uruguay or Jamaica or Trinidad or Tobago or Guyana or Suriname or Belize or Bahamas or Barbados or St Lucia or Saint Lucia or Grenada or St Vincent or Saint Vincent or Grenadines or Antigua and Barbuda or Dominica or Saint Kitts or St Kitts or Nevis).mp.	
4	Or/1-3	Latin America and the Caribbean
5	(disable* or Disabilit* or Handicap*) adj5 (person* or people).mp.	
6	(Physical* adj5 (impair* or deficienc* or disable* or disabili* or handicap*)).mp.	
7	(Cerebral pals* or Spina bifida or Muscular dystroph* or Arthriti* or Osteogenesis imperfecta or Musculoskeletal abnormalit* or Musculo-skeletal abnormalit* or Muscular abnormalit* or Skeletal abnormalit* or Limb abnormalit* or Amputation* or Clubfoot or Poliomyeliti* or Paraplegi* or Paralys* or Paralyz* or Hemiplegi*).mp.	
8	((Hearing or Acoustic or Ear*3) adj5 (loss* or impair* or deficienc* or disable* or disabili* or handicap*)).mp.	
9	((Visual* or Vision or Eye*3) adj5 (loss* or impair* or deficienc* or disable* or disabili* or handicap*)).mp.	
10	(Deaf* or Blind*).mp.	
11	exp Hearing impairment/ or exp vision disorders/ or exp Deafness/ or exp Blindness/	
12	(Schizophreni* or Psychosis or Psychoses or Psychotic Disorder* or Schizoaffective Disorder* or Schizophreniform Disorder* or Dementia* or Alzheimer*).mp.	
13	exp "schizophrenia and disorders with psychotic features"/ or exp Dementia/ or exp Alzheimer disease/	

14	((Intellectual* or Mental* or Psychological* or Developmental) adj5 (impair* or retard* or deficienc* or disable* or disabili* or handicap* or ill?6)).mp.	
15	((communication or language or speech or learning) adj5 disorder* or disabilit*).mp.	
16	(Autis* or Dyslexi* or Down* Syndrome or Mongolism or Trisomy 21).mp.	
17	exp Learning Disorders/	
18	exp Mentally Disabled Persons/	
19	Or/5-18	Disability search terms
20	exp Immunization/	
21	exp Immunization Programs/	
22	exp Health Services/	
23	exp Mass Screening/	
24	exp health program/	
25	exp health care/	
26	access*.mp.	
27	health*.mp.	
28	equal*.mp.	
29	inequal*.mp.	
30	barrier*.mp.	
31	exp Preventive Health Services/ or exp Health Services for Persons with Disabilities/ or exp Primary Health Care/ or exp Health Promotion/	
32	exp Palliative Care/	
33	palliat*.mp.	
34	promot*.mp.	
35	health promot*.mp.	
36	prevent*.mp.	
37	(access* or afford* or accept* or avail* or "geographic avail*").mp.	
38	facilitat*.mp.	
39	Or/20-38	Healthcare access
40	4 and 19 and 39	Final search
41	Limit 40 to yr="2000 -Current"	Final search between 2000-current

CINAHL

#	Searches	Annotations
3	Guadaloupe or Aruba or Martinique or Turks or Caicos or “Turks and caicos islands” or “virgin islands” or Peru or Argentina or Brazil or Chile or Colombia or Venezuela or Cayman Or Puerto Rico Or “Saint Barthelemy” or ”ST Barthelemy” or Guatemala or Ecuador or Bolivia or Haiti or Cuba or “Dominican Republic” or Honduras or Paraguay or Nicaragua or ”El Salvador” or ”Costa Rica” or Panama or Uruguay or Jamaica or Trinidad or Tobago or Guyana or Suriname or Belize or Bahamas or Barbados or St Lucia or Saint Lucia or Grenada or “St Vincent” or “Saint Vincent” or Grenadines or Antigua and Barbuda or Dominica or “Saint Kitts” or “St Kitts” or Nevis	
4	Or/1-3	Latin America and the Caribbean
5	(disable* or Disabilit* or Handicap*) n5 (person* or people))	
6	(Physical* n5 (impair* or deficienc* or disable* or disabili* or handicap*))	
7	(“Cerebral pals*“ or “Spina bifida“ or “Muscular dystroph*“ or Arthriti* or “Osteogenesis imperfecta“ or “Musculoskeletal abnormalit*“ or “Musculo-skeletal abnormalit*“ or “Muscular abnormalit*“ or “Skeletal abnormalit*“ or “Limb abnormalit*“ or Amputation* or Clubfoot or Poliomyeliti* or Paraplegi* or Paralys* or Paralyz* or Hemiplegi*)	
8	((Hearing or Acoustic or Ear*) n5 (loss* or impair* or deficienc* or disable* or disabili* or handicap*))	
9	((Visual* or Vision or Eye*) n5 (loss* or impair* or deficienc* or disable* or disabili* or handicap*))	
10	(Deaf* or Blind*)	
11	“Hearing impairment*” or “vision disorder*” or Deafness or Blindness	
12	(Schizophreni* or Psychosis or Psychoses or “Psychotic Disorder*” or “Schizoaffective Disorder*” or “Schizophreniform Disorder*” or Dementia* or Alzheimer*)	
14	((Intellectual* or Mental* or Psychological* or Developmental) n5 (impair* or retard* or deficienc* or disable* or disabili* or handicap* or ill or illness)	
15	((communication or language or speech or learning) n5 disorder* or disabilit*)	
16	(Autis* or Dyslexi* or “Down* Syndrome” or Mongolism or “Trisomy 21”)	
17	Learning Disorders	

18	exp Mentally Disabled Persons/	
19	Or/5-18	Disability search terms
20	(MH "Immunization+")	
21	(MM "Immunization Programs")	
22	(MH "Health Services+")	
23	(MH "Health Screening+")	
24	"health program*"	
25	(MH "Outcomes (Health Care)+") OR (MH "Health Services Needs and Demand+") "Health care" or "healthcare"	
26	access*	
27	health*	
31	“Preventive Health Service*” or “Health Service* for Person* with Disabilit*” or “Primary Health Care” “Health Promotion”	
32	(MM "Palliative Care")	
35	(MH "Health Promotion") OR (MH "Preventive Health Care+")	
37	(access* or afford* or accept* or avail* or "geographic avail*")	
39	Or/20-38	Healthcare access
40	4 and 19 and 39	Final search
41	Limit 40 to yr="2000 -Current"	Final search between 2000-2020

LILACS

((pessoa* and deficiência*) OR (disabled and person*) OR (persona* and discapacidad*) OR (pessoa* com incapacidade*) OR (pessoa* com deficiência*) OR (pessoa* com limitação física) OR (pessoas com limitações físicas) OR (pessoa* com necessidade* especial*) OR (persona con discapacidad) OR (persona con limitación física) OR (personas con limitaciones físicas) or Schizophreni*” or Psychosis or Psychoses or (Psychotic Disorder*) or (Schizoaffective Disorder*) or Dementia* or Alzheimer* OR ((Hearing or Acoustic or Ear*) AND (loss* or impair* or deficienc* or disable* or disabili* or handicap*)) OR ((Visual* or Vision or Eye*) AND (loss* or impair* or deficienc* or disable* or disabili* or handicap*)) OR ((Intellectual* or Mental* or Psychological* or Developmental) AND (impair* or retard* or deficienc* or disable* or disabili* or handicap* or ill or illness)) or ((communication or language or speech or learning) and (disorder* or disabiliti*)) or Autis* or Dyslexi* or (Down* Syndrome) or Mongolism or (Trisomy 21)) AND ((acesso aos serviços de saúde) OR (health services accessibility) OR (accesibilidad a servicios de salud) OR (disparidades em assistência à saúde) OR (healthcare disparities) OR (disparidades en atención de salud) OR (serviços de saúde para pessoas com deficiência) OR (health services for persons with disabilities) OR (servicios de salud para personas con discapacidad) OR (healthcare) OR (Health care) OR (preventative care) OR (Saúde preventiva) OR (salud preventiva)) AND (Guadaloupe or Aruba or Martinique or Turks or Caicos or (Turks and caicos) or (virgin islands) or Peru or Argentina or Brazil or Brasil or Chile or Colombia or Venezuela or Cayman Or Puerto Rico Or (Saint Barthelemy) or (ST Barthelemy) or Guatemala or Ecuador or Bolivia or Haiti or Cuba or (Dominican Republic) or (Republica Dominicana) or Honduras or Paraguay or Nicaragua or (El Salvador) or (Costa Rica) or Panama or Uruguay or Uruguai or Jamaica or Trinidad or Tobago or Guyana or Guiana or Suriname or Belize or Bahamas or Barbados or (St Lucia) or (Saint Lucia) or Grenada or (St Vincent) or (Saint Vincent) or Grenadines or (Antigua and Barbuda) or Dominica or (Saint Kitts) or (St Kitts) or Nevis or (south america) or (west indies) or Caribbean or (latin america) or (central America))

ENTREQ Checklist

Supplementary File S3: ENTREQ (Enhancing transparency in reporting the synthesis of qualitative research) Checklist

No	Item	Guide and Description	Reported on page #
1	**Aim**	State the research question the synthesis addresses.	3
2	**Synthesis methodology**	Identify the synthesis methodology or theoretical framework which underpins the synthesis, and describe the rationale for choice of methodology *(e.g. meta-ethnography, thematic synthesis, critical interpretive synthesis, grounded theory synthesis, realist synthesis, meta-aggregation, meta-study, framework synthesis).*	5-6
3	**Approach to searching**	Indicate whether the search was pre-planned (*comprehensive search strategies to seek all available studies)* or iterative (*to seek all available concepts until they theoretical saturation is achieved)*.	5-6
4	**Inclusion Criteria**	Specify the inclusion/exclusion criteria *(e.g. in terms of population, language, year limits, type of publication, study type).*	5-6
5	**Data Sources**	Describe the information sources used (e.g. *electronic databases (MEDLINE, EMBASE, CINAHL, psycINFO, Econlit), grey literature databases (digital thesis, policy reports), relevant organisational websites, experts, information specialists, generic web searches (Google Scholar) hand searching, reference lists)* and when the searches conducted; provide the rationale for using the data sources.	5-6
6	**Electronic search strategy**	Describe the literature search *(e.g. provide electronic search strategies with population terms, clinical or health topic terms, experiential or social phenomena related terms, filters for qualitative research, and search limits)*.	Additional document named 'search terms'
7	**Study screening methods**	Describe the process of study screening and sifting *(e.g. title, abstract and full text review, number of independent reviewers who screened studies).*	5-6
8	**Study characteristics**	Present the characteristics of the included studies *(e.g. year of publication, country, population, number of participants, data collection, methodology, analysis, research questions).*	Additional document named 'table 1 eligible studies'
9	**Study selection results**	Identify the number of studies screened and provide reasons for study exclusion *(e,g, for comprehensive searching, provide numbers of studies screened and reasons for exclusion indicated in a figure/flowchart; for iterative searching describe reasons for study exclusion and inclusion based on modifications t the research question and/or contribution to theory development).*	Additional document named 'PRISMA

			flow diagram’
10	**Rationale for appraisal**	Describe the rationale and approach used to appraise the included studies or selected findings *(e.g. assessment of conduct (validity and robustness), assessment of reporting (transparency), assessment of content and utility of the findings).*	5-6
11	**Appraisal items**	State the tools, frameworks and criteria used to appraise the studies or selected findings *(e.g. Existing tools: CASP, QARI, COREQ, Mays and Pope*[25]*; reviewer developed tools; describe the domains assessed: research team, study design, data analysis and interpretations, reporting).*	5-6
12	**Appraisal process**	Indicate whether the appraisal was conducted independently by more than one reviewer and if consensus was required.	5-6
13	**Appraisal results**	Present results of the quality assessment and indicate which articles, if any, were weighted/excluded based on the assessment and give the rationale.	Additional document named ‘table 2 COREQ’
14	**Data extraction**	Indicate which sections of the primary studies were analysed and how were the data extracted from the primary studies? *(e.g. all text under the headings “results /conclusions” were extracted electronically and entered into a computer software).*	5-6
15	**Software**	State the computer software used, if any.	5-6
16	**Number of reviewers**	Identify who was involved in coding and analysis.	5-6
17	**Coding**	Describe the process for coding of data *(e.g. line by line coding to search for concepts).*	5-6
18	**Study comparison**	Describe how were comparisons made within and across studies *(e.g. subsequent studies were coded into pre-existing concepts, and new concepts were created when deemed necessary).*	5-6
19	**Derivation of themes**	Explain whether the process of deriving the themes or constructs was inductive or deductive.	7
20	**Quotations**	Provide quotations from the primary studies to illustrate themes/constructs, and identify whether the quotations were participant quotations of the author’s interpretation.	7-15
21	**Synthesis output**	Present rich, compelling and useful results that go beyond a summary of the primary studies (e.g. *new interpretation, models of evidence, conceptual models, analytical framework, development of a new theory or construct).*	7-15

From: Tong A, Flemming K, McInnes E, et al.. Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ. BMC Medical Research Methodology 2012, 12:181.

PRISMA Checklist

PRISMA-DTA Checklist

			‘search terms’
			‘Prisma diagram’

PRISMA-DTA Checklist

Section/topic	#	PRISMA-DTA Checklist Item	Reported on page #
Definitions for data extraction	11	Provide definitions used in data extraction and classifications of target condition(s), index test(s), reference standard(s) and other characteristics (e.g. study design, clinical setting).	5 and 6
Risk of bias and applicability	12	Describe methods used for assessing risk of bias in individual studies and concerns regarding the applicability to the review question.	NA
Diagnostic accuracy measures	13	State the principal diagnostic accuracy measure(s) reported (e.g. sensitivity, specificity) and state the unit of assessment (e.g. per-patient, per-lesion).	NA
Synthesis of results	14	Describe methods of handling data, combining results of studies and describing variability between studies. This could include, but is not limited to: a) handling of multiple definitions of target condition. b) handling of multiple thresholds of test positivity, c) handling multiple index test readers, d) handling of indeterminate test results, e) grouping and comparing tests, f) handling of different reference standards	5 and 6
Meta-analysis	D2	Report the statistical methods used for meta-analyses, if performed.	NA
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	NA
RESULTS			
Study selection	17	Provide numbers of studies screened, assessed for eligibility, included in the review (and included in meta-analysis, if applicable) with reasons for exclusions at each stage, ideally with a flow diagram.	7 and additional document named 'Prisma flow diagram'
Study characteristics	18	For each included study provide citations and present key characteristics including: a) participant characteristics (presentation, prior testing), b) clinical setting, c) study design, d) target condition definition, e) index test, f) reference standard, g) sample size, h) funding sources	Additional document named 'Table 1 eligible studies'
Risk of bias and applicability	19	Present evaluation of risk of bias and concerns regarding applicability for each study.	NA
Results of individual studies	20	For each analysis in each study (e.g. unique combination of index test, reference standard, and positivity threshold) report 2x2 data (TP, FP, FN, TN) with estimates of diagnostic accuracy and confidence intervals, ideally with a forest or receiver operator characteristic (ROC) plot.	NA

Appendix 2. Supporting information for Paper Two

Study information sheet

International Centre for Evidence in Disability

Access to Healthcare and Rehabilitation for People with Disabilities in Brazil

Information Sheet: In-depth interviews (Person with disabilities)

We are inviting you to take part in a research study. Before you decide whether or not to participate, it is important that you know why we are doing the study and what is involved. Please read the following information carefully.

What is the study?
We are talking to adults with disabilities in Brasilia, Pernambuco and São Paulo about experiences receiving primary healthcare or rehabilitation services and healthcare stakeholders about their experiences providing primary healthcare services or rehabilitation services for people with disabilities.

Why are we doing the study?
We would like to better understand how to promote inclusion of people with disability into the Brazilian public health system.

What will happen to the results of the research study?
We hope to publish the results in a peer-reviewed article.
Findings will be fed back to inform policymakers.
Findings will be shared in an end of project meeting with key informants.

Do I have to take part?
No, it is up to you to decide whether to take part. There will be no repercussions if you do not participate and no inference will be drawn from you not wanting to participate.

What will happen if I take part?
A researcher will contact you to arrange a convenient time and place for an interview; it can take place anywhere is most convenient to you. During the interview, we will ask you about your experience accessing primary or rehabilitation healthcare services.
With your permission, we will audio record the interview, which we will only use to ensure that we have an accurate account of what you said. These recordings will then be transcribed. If you do not give permission for the interview to be recorded then the researcher will take notes.
You are free to answer any questions you want and we can skip any questions you would prefer not to answer.
The interview will take approximately one hour.

What do I have to do?
If you agree to take part you will need to read and sign the consent form.

What are the alternatives?
You could recommend this study to a person who might be interested in participating.
We can start the interview and, if you see it is not something you want to take part in, we can stop at any moment and the data collected from you will not be used.
You do not have to take part.

What are the possible benefits of taking part?
There is no direct benefit from taking part in the interview, but we hope that it will contribute to better understanding and improving the inclusion of people with disabilities into the Brazilian healthcare system.

What will happen if I don't want to carry on with the study?
You can withdraw from the study during the interview, after the interview and just before your quotes have been published in a paper by informing one of the researchers listed below or the researcher conducting your interview.

Will my taking part in this study be kept confidential?
Yes. Your comments will be identified by a research number only and we will not use your name. If there is something that you want to tell use that is particularly confidential/sensitive and you want to be certain that it is not attributed to you in anyway please let us know and we will ensure full anonymity.

Who is organising the research?
The study is being run by the London School of Hygiene and Tropical Medicine in collaboration with Fiocruz Pernambuco, Fiocruz Brasilia and University of São Paulo Medical School General Hospital.

Who has reviewed the study?
The London School of Hygiene and Tropical Medicine (LSHTM) ethics committee.
University of São Paulo Medical School General Hospital.

Who can I contact for more information or future updates?

Hannah Kuper
hannah.kuper@lshtm.ac.uk

Loveday Penn-Kekana
loveday.penn-kekana@lshtm.ac.uk

Veronika Reichenberger
veronika.reichenberger@lshtm.ac.uk

Vinícius Delgado Ramos
Vinicius.ramos@hc.fm.usp.br

Interview guide

Strengthening healthcare access of people with disabilities in Brazil
INTERVIEW GUIDE: Person with disability

Purpose: To gain insights into people with disabilities access to healthcare services and their experiences when accessing or receiving care.

Materials:

- Notepad and pen/s
- Tape recorder

NOTE: Copies of relevant local policies, posters, or other materials may be used to help stimulate discussion if appropriate.

Introduction:
Hello and thank you for your time. I am (Interviewer's name) from...........
I would like to spend some time talking to you about your use of healthcare services and how you make decisions about healthcare.

Remind them of the issue of confidentiality and anonymity which is fully explained in the information and consent form that they completed. Check if they have any questions from the information and consent form about the research. Remind them that they are free to decline to answer any of the questions or stop the interview at any time.

Background Information

Interview Date and Time		
Interviewer		
Language of Interview		
Interview location (home, etc.)		
Town/State		
Gender	**Male**	**Female**
Age		
Marital Status		
General Observations: **(Anything which might impact how the interview is conducted, e.g. other present.)**		

A. About Themselves:

1. Please tell me about yourself (work, study, family, what is your routine generally like)

2. Please tell me about your family/household?
   Prompts: Sources of income? Is there anyone else in the household who has major illness or disability? If so, who and what is their condition?

B. About disability:

3. Please tell me about your impairment?
   Prompts: Time of onset? If appropriate, ask what happened?

4. Do you have any difficulties in doing everyday activities? Does your impairment limit you in doing the things you need or want to do? How?

5. Do you need help to do the things you need to do every day? If so, do you receive any help or support from family or friends? What kind of support?
   Prompts: Daily activities such as going to the bathroom, dressing, eating, going out - Who helps or supports them and how? If yes, who and how? If not, why do you think that is?

C. Health Status and seeking services:

6. How would you describe your health at this time?

Prompts: Do you have any health concerns? What is the main one that worries you? What are any co-morbidities you might have due to/caused by your impairment (if applicable)?

7. In the last 6 months, what are all the healthcare services you've used? And for what reasons? (Examples: pharmacy, doctor, healer, clinic, hospital)?
   a. Could you talk me through your journey (how did you identify the need and then seeing a doctor).
   b. When thinking of seeking health services what are the different things you think about? How do you make healthcare decisions; does anyone do it for you or you make the decisions yourself? Does your impairment influence your decisions? If so, how and why?
   c. Have you had any rehabilitation or assistive technology service? Which ones? How was your access to them and how was the service?
   d. If not, do you think you could have benefited from it/them? How?

D. Experiences while receiving healthcare services:

8. When was the last time you went to clinic/hospital…………..
   Prompts: How was your experience? Could you tell us step by step? How do you get to the clinic? At the clinic: how was physical accessibility, signage, experience of health care providers, price, equipment for their specific needs, denied care/treated differently from other patients? What worked well and what was difficult?

9. Thinking of the last two appointments you had at any SUS clinic, tell me about your experiences: What were the reasons you sought health care services? How was it?

10. Do you ever use private? When/why?

11. Have you ever been ill and didn’t access health services? Why? Focus on last two times.

E. Overall thoughts on access to healthcare services:

12. Do you feel that your healthcare needs are met?
    Prompts: What does having access to healthcare mean? Do you think that your health care needs are the same or different from people who don’t have your impairment/disability? Do you feel you receive the same or different quality of healthcare services as others? Do you feel you are treated same or differently?

13. Do you know of any programs or services that can help people who have difficulty accessing health services? If so, can you tell me about them?

14. Do you have any thoughts on what can make it easier for you to seek or access healthcare services (Examples: physical access, training, treatment options, social interactions, education materials, etc.)?

15. In these specific scenarios, how should a healthcare provider go about them:
    a. A blind woman is seeking contraception.
    b. A deaf man wants to talk to a healthcare professional about his depression and his mother is there to support with sign language.
    c. A man who is a wheelchair user thinks he needs to lose weight.

F. Other Information:

Are there any other important issues which we haven’t covered which you would like to comment on or that you feel are important to addressing access to healthcare for people with disability?

Thank you for taking the time to talk with me/us today. We have learned a great deal from you and your experiences.

Consent form

CONSENT FORM - Study on Access to Healthcare and Rehabilitation for People with Disabilities in Brazil.

Participant name: (First & Last Name)_______________________________________

Subject No: ____ ____

1. The information sheet concerning this study has been read to me and I understand what is required of me/the participant if I take part in it.
2. I understand that information about me/the participant may be shared directly with other researchers, and that I will not be identifiable from this information.
3. I have been given the opportunity to ask questions and a reply was given for all the questions to my satisfaction.
4. I understand that participation is voluntary and that I may withdraw at any time without giving a reason.
5. Expressed by ticking one of the boxes below, I consent/do not consent for the researcher to audio record my interview for the purpose of improving the accurately of reporting what was said only:

☐ I consent to being audio recorded during the interview

☐ I do **not** consent to being audio recorded during the interview

---

Consent to participate

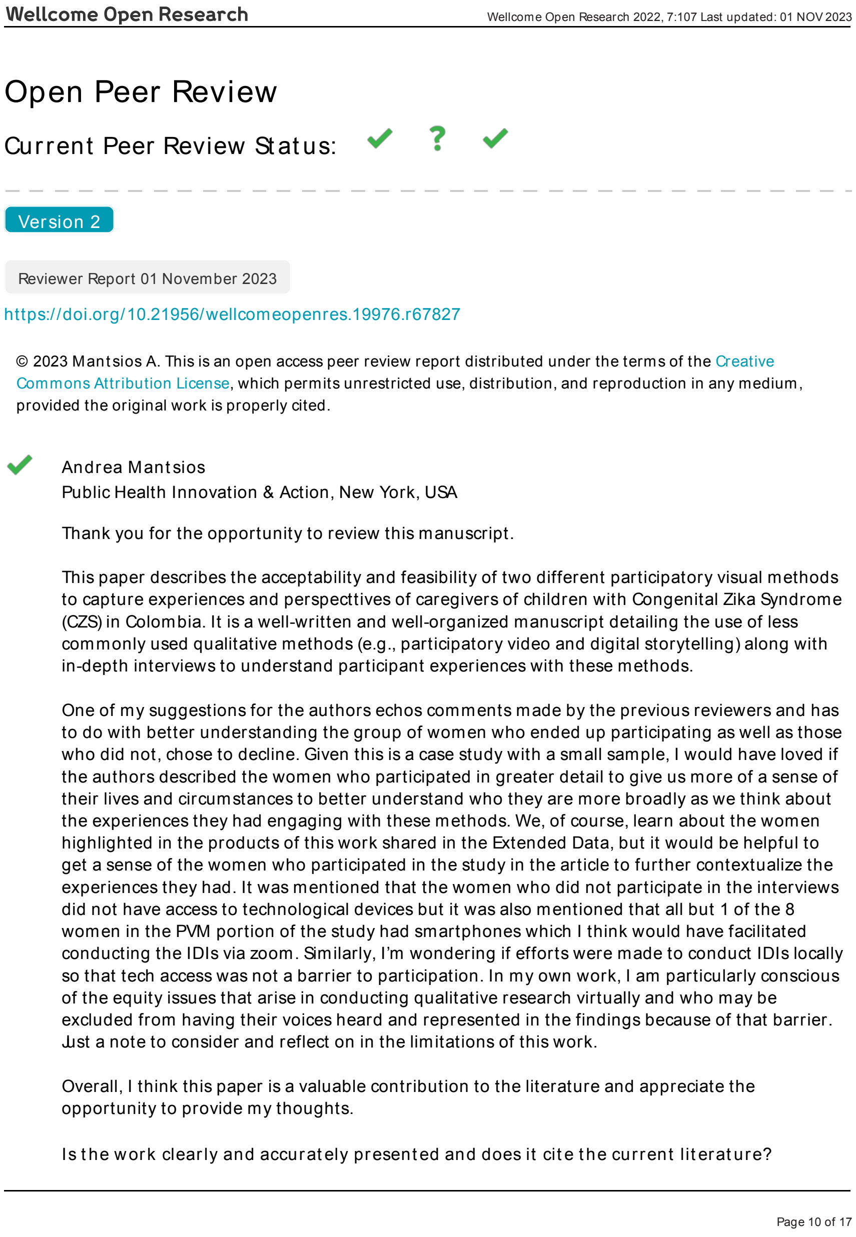
Name of participant/representative	Date	Signature/Thumbprint
Name of impartial witness	Date	Signature

I attest that I have explained the study information accurately, and was understood to the best of my knowledge by, the participant and that he/she has freely given their consent to participate in the presence of the above named impartial witness (where applicable).

Name of person obtaining consent	Date	Signature

Appendix 3. Supporting information for Paper Three

Wellcome open peer review reviewer feedback



Wellcome Open Research Wellcome Open Research 2022, 7:107 Last updated: 01 NOV 2023

Open Peer Review

Current Peer Review Status: ✓ ? ✓

Version 2

Reviewer Report 01 November 2023

https://doi.org/10.21956/wellcomeopenres.19976.r67827

✓

Andrea Mantsios
Public Health Innovation & Action, New York, USA

Thank you for the opportunity to review this manuscript.

This paper describes the acceptability and feasibility of two different participatory visual methods to capture experiences and perspecttives of caregivers of children with Congenital Zika Syndrome (CZS) in Colombia. It is a well-written and well-organized manuscript detailing the use of less commonly used qualitative methods (e.g., participatory video and digital storytelling) along with in-depth interviews to understand participant experiences with these methods.

One of my suggestions for the authors echos comments made by the previous reviewers and has to do with better understanding the group of women who ended up participating as well as those who did not, chose to decline. Given this is a case study with a small sample, I would have loved if the authors described the women who participated in greater detail to give us more of a sense of their lives and circumstances to better understand who they are more broadly as we think about the experiences they had engaging with these methods. We, of course, learn about the women highlighted in the products of this work shared in the Extended Data, but it would be helpful to get a sense of the women who participated in the study in the article to further contextualize the experiences they had. It was mentioned that the women who did not participate in the interviews did not have access to technological devices but it was also mentioned that all but 1 of the 8 women in the PVM portion of the study had smartphones which I think would have facilitated conducting the IDIs via zoom. Similarly, I'm wondering if efforts were made to conduct IDIs locally so that tech access was not a barrier to participation. In my own work, I am particularly conscious of the equity issues that arise in conducting qualitative research virtually and who may be excluded from having their voices heard and represented in the findings because of that barrier. Just a note to consider and reflect on in the limitations of this work.

Overall, I think this paper is a valuable contribution to the literature and appreciate the opportunity to provide my thoughts.

Is the work clearly and accurately presented and does it cite the current literature?

Yes

Is the study design appropriate and is the work technically sound?
Yes

Are sufficient details of methods and analysis provided to allow replication by others?
Yes

If applicable, is the statistical analysis and its interpretation appropriate?
Not applicable

Are all the source data underlying the results available to ensure full reproducibility?
Yes

Are the conclusions drawn adequately supported by the results?
Yes

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Qualitative research, caregivers of children with CZS in Brazil, HIV

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.

Reviewer Report 26 August 2022

https://doi.org/10.21956/wellcomeopenres.19976.r51477

✓

Debora Diniz
The Center for Latin American and Caribbean Studies, Brown University, Providence, RI, USA

Thanks for submitting the article to my second reading.

The authors did a great work addressing the comments and making clearer some of the previous questions, particularly regarding the methods and the participants description.

The article should be approved.

Is the work clearly and accurately presented and does it cite the current literature?
Yes

Is the study design appropriate and is the work technically sound?

Yes

Are sufficient details of methods and analysis provided to allow replication by others?
Yes

If applicable, is the statistical analysis and its interpretation appropriate?
Yes

Are all the source data underlying the results available to ensure full reproducibility?
Yes

Are the conclusions drawn adequately supported by the results?
Yes

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: My area of research is also Zika, women and visual methods

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.

Version 1

Reviewer Report 20 June 2022

https://doi.org/10.21956/wellcomeopenres.19381.r50828

?

Ignacio Zarante
Human Genetics Institute, Pontificia Universidad Javeriana, Bogota, Colombia

This is an article where participatory visual methods are used in families of patients with sequelae of prenatal Zika virus infection in the city of Cali, Colombia. They search for 11 families, but in the end they only manage to complete the qualitative research in 4 of them. Families should develop a digital storytelling or participatory video. Each caregiver and family was taught how to operate the camera and instructed to develop a script with the help of the researchers. These scripts were developed together and shared with the other families the experience they were developing. At the end, the information was analyzed using semi-structured in-depth interviews.

The results are remarkably interesting since the whole process generated participatory work within the family and contact with the others. It is evident that this strategy has a great feasibility to empower families with members who are disabled. The limitation of the methods was in a small sample that also ended with a small number of participants. The conclusions are interesting, but it is not so easy to extrapolate the results to larger groups. The authors do not give much information on the reasons why some of those involved did not participate and there may be explanations for the usefulness of these strategies.

Is the work clearly and accurately presented and does it cite the current literature?
Yes

Is the study design appropriate and is the work technically sound?
Partly

Are sufficient details of methods and analysis provided to allow replication by others?
Yes

If applicable, is the statistical analysis and its interpretation appropriate?
Not applicable

Are all the source data underlying the results available to ensure full reproducibility?
Yes

Are the conclusions drawn adequately supported by the results?
Partly

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Birth defects, medical genetics, public health

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.

Author Response 29 Jun 2022
Veronika Reichenberger

Dear Ignacio Zarante,

Thank you for your comments and review. We are honoured to get your important feedback on our paper.

We are also very pleased to read you found the results interesting.

With regards to not being able to extrapolate to a larger group, we have added a sentence clarifying this in the last paragraph of the results, which now states:

“Additionally, only four participants were involved in both methods forming the basis for this case study. Therefore, the results cannot be extrapolated to a larger group.”

We are please to inform that we have also added more information on the reasons why we did not have more participants involved. A new sentence found in the first paragraph of the results section, now states:

"The other four participants did not take part in the DST and in-depth interview because of lack of time and no access to technological devices."

We hope to have provided appropriate clarification and are available for further exchanges and modifications where needed.

Competing Interests: No competing interests were disclosed.

Reviewer Report 13 April 2022

https://doi.org/10.21956/wellcomeopenres.19381.r49405

? Debora Diniz
The Center for Latin American and Caribbean Studies, Brown University, Providence, RI, USA

The research article describes the methodological processes involved in using visual research tools with women affected by the Zika epidemic in Colombia. It's a descriptive study about how the visual tools facilitated gathering information about the research question. The group of women involved in this research initiative was small and some of them decided to step down during the process, which was not clarified by the authors. I appreciate the opportunity to read the manuscript in advance and I hope that my comments will help the authors to further develop such an important initiative:

1. Power dynamics, Empowerment

I would not describe the visual tools as mechanisms of "giving power" to participants. It's more about sharing than giving, and the replacement of verbs here is not just rhetorical: it is also deeply conceptual. It is about how the researchers understand their roles and purpose in using visual tools in the context of a research interaction. Why am I mentioning this point? The study presents two purposes for using visual tools in social research: as a way of engaging participants and as a tool for "concientizacao" or "empowerment" (as presented in the manuscript, these two concepts are not interchangeable; but the content of each one is not that clear). The first purpose is clearly stated in the descriptive narrative about the processes involved in working with different visual methodologies. The second purpose is not that straightforward, however, and I wonder if the authors should consider eliminating it. There is no evidence in the study that the visual methods empowered women: the example of one of the participants referring to "writ[ing] a book about her son" is more a regional way of expressing the idea that "I'm going to tell my story" than the literal intention to initiate a new project. I do not see the meetings for visual literacy as reflecting the concept of engaged pedagogy conceptualized by Paulo Freire or bell hooks. Finally, in my opinion, the concept of "hearing" and "being heard" by others is a key emic concept yet it was not explored by the authors as a key element of using visual methodologies.

2. Caregivers, women, disability

The study was conducted among women. Yet gender is absolutely ignored by the manuscript. The study refers to them as "caregivers" or "mothers" or “grandmother”. We have no other information about them, just that their visual literacy was low - an observation that I question considering the levels of digital inclusion in Colombia via the use of smartphones. We need to know more about who these women are, beyond their social roles as caregivers of children affected by the Zika congenital syndrome. In a brief reflective sentence about the positionality of the facilitator, s/he mentions that s/he is not disabled nor a carer of a child with disability. But why only mention disability here if the work was among women? Why not also consider race, class, education, gender, nationality, as crucial factors to understand the research framing and the power dynamics?

3. Minor comments

I would encourage the authors to confirm if there is any updated data about Zika cases among pregnant women in Colombia. The study mentions April 2016 as the reference. I would also consider reorganizing the arguments, in case the authors prefer to maintain the argument of empowerment/conscientizacao. If they keep that argument, my recommendation would be to incorporate it as part of the analysis of the results and not as an assumption in the Introduction.

I deeply admire the study and the ethical commitment that led the authors to work with visual methods, particularly recognizing how rare and demanding it is. I'm more than happy and available to reconsider my comments if the authors do not consider them appropriate for what they have in mind.

Is the work clearly and accurately presented and does it cite the current literature?
Yes

Is the study design appropriate and is the work technically sound?
Partly

Are sufficient details of methods and analysis provided to allow replication by others?
Yes

If applicable, is the statistical analysis and its interpretation appropriate?
Not applicable

Are all the source data underlying the results available to ensure full reproducibility?
Yes

Are the conclusions drawn adequately supported by the results?

Partly

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: My area of research is also Zika, women and visual methods

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.

Author Response 29 Jun 2022

Veronika Reichenberger

Dear Debora Diniz,

Thank you very much for your review and request for clarification. It’s an honour to receive a review from such a prestigious academic as yourself.

1. Power dynamics, Empowerment

We would like to clarify our reasoning behind mentioning empowerment in the introduction. We were pleased to include background in the introduction to assist the reader in understanding certain concepts such as empowerment, which is a recognized concept within PV (as referenced by Caroline Wang in her extensive work with participatory visual methods such as photovoice).

With regards to writing the book, we understand the space for interpretation this left. We would like to clarify that beyond mentioning wanting to write a book, the participant went into more detail, including questions regarding publishing, which supported the understanding of wanting to write a book as opposed to an expression.

2. Caregivers, women, disability

As suggested, we provided more information about who the women are after the quotes to assist the readers. We have added age group and occupation. (Example: Participant 2, 30-40 years old, housewife)

We are pleased to highlight that the reflective sentence does include more details about the facilitator, as mentioned in the last paragraph before the ethics, in the methods section: “One female researcher (VR) was involved in all three phases of the study. She has previous training in both PV and DST, as well as qualitative research. She is a research assistant and PhD candidate at the London School of Hygiene and Tropical Medicine. She is of Brazilian descent and speaks Spanish fluently. She is not disabled herself and is not the carer of a child with disabilities.”

We have also added a sentence to clarify about the participants visual literacy:
“All of them, but one participant, have smartphones and have previously experienced taking

pictures and making videos on their phones."
We also added "cinematographic techniques" to support the understanding that the new skills were specific to these techniques (lighting, angles, using a camcorder) as opposed to making a video itself, which all but one had already done.

Thank you for these important comments and requests.

3. Minor comments

We would like to clarify the reasoning behind the 2016 status. The zika epidemic went from 2015 to 2016, which is when Congenital Zika Syndrome was identified. This is hence the focus of our study and believe the statistics from 2016 provide better understanding on the background of the study than recent statistics.

We are honoured to hear you admire the study and recognize how rare and demanding it can be.

We hope to have clarified your comments and are available for further exchanges and clarifications where needed.

Competing Interests: No competing interests were disclosed.

Participatory Video first consent form for children (Spanish)

AUTORIZACION DE USO DE NOMBRE, IMAGEN Y TESTIMONIALES

Yo,____ mayor de edad identificado (a) con la cédula de ciudadanía. No.____________________ de __________, Colombia, en representación legal del menor de edad___________________________________, en uso de mis plenas facultades, autorizo a **FUNDACIÓN CASA GAMI -Grupo de Apoyo a la Mujer y al Infante y London School of Hygiene and Tropical Medicine (LSHTM)**, o a quien éste designe, para que use el nombre, imagen, frases, declaraciones, testimoniales y retrato del niño/a fruto de las grabaciones de audio y video que concedió de manera libre y voluntaria en el **video participativo sobre el impacto del programa Juntos.**

La utilización del nombre, frases, declaraciones, testimoniales y retrato del niño/a podrá realizarse mediante la divulgación a través de su reproducción, tanto en medios digitales (sitio web de LSHTM, redes sociales, y espacios digitales de organizaciones vinculadas a Casa Gami) así como en conferencias, aulas, reuniones con partes interesadas y en medios impresos (en forma de fotos y testimoniales).

Manifiesto que esta autorización la otorgo con carácter gratuito, por lo que entiendo que no recibiré ni solicitaré ningún tipo de compensación extra, bonificación extra o pago extra de ninguna naturaleza. La vigencia de esta autorización será a perpetuidad, durante la existencia del **video participativo sobre el impacto del programa Juntos**, contados desde la fecha de la firma de este documento.

Reconozco además que no tengo ninguna expectativa sobre el tipo de campaña publicitaria que pueda realizar **FUNDACIÓN CASA GAMI -Grupo de Apoyo a la Mujer y al Infante y London School of Hygiene and Tropical Medicine** o quien esta designe, ni su regularidad y, que renuncio a cualquier derecho patrimonial que se pueda generar por el uso de esta grabación.

He leído el presente documento antes de firmarlo y garantizo que comprendo el contenido del mismo. Se firma el día_______del mes de _______________de 20___.

Atentamente,

___________________________ ___________________________
NOMBRE FIRMA

C.C.____________________

Teléfono:_______________

Participatory Video first consent form for adults (Spanish)

AUTORIZACIÓN DE USO DE NOMBRE, IMAGEN Y TESTIMONIALES

Yo, ____ mayor de edad identificado (a) con la cédula de ciudadanía. No.____________________ de _______, Colombia, en uso de mis plenas facultades, autorizo a **FUNDACIÓN CASA GAMI -Grupo de Apoyo a la Mujer y al Infante y London School of Hygiene and Tropical Medicine (LSHTM)**, o a quien éste designe, para que use mi nombre, imagen, frases, declaraciones, testimoniales y retrato fruto de las grabaciones de audio y video que concedí de manera libre y voluntaria en el **video participativo sobre el impacto del programa Juntos.**

La utilización de mi nombre, frases, declaraciones, testimoniales y retrato realizarse mediante la divulgación a través de su reproducción, tanto en medios digitales (sitio web de LSHTM, redes sociales, y espacios digitales de organizaciones vinculadas a Casa Gami) así como en conferencias, aulas, reuniones con partes interesadas y en medios impresos (en forma de fotos y testimoniales).

Manifiesto que esta autorización la otorgo con carácter gratuito, por lo que entiendo que no recibiré ni solicitaré ningún tipo de compensación extra, bonificación extra o pago extra de ninguna naturaleza. La vigencia de esta autorización será a perpetuidad, durante la existencia del **video participativo sobre el impacto del programa Juntos**, contados desde la fecha de la firma de este documento.

Reconozco además que no tengo ninguna expectativa sobre el tipo de campaña publicitaria que pueda realizar **FUNDACIÓN CASA GAMI -Grupo de Apoyo a la Mujer y al Infante y London School of Hygiene and Tropical Medicine (LSHTM)** o quien esta designe, ni su regularidad y, que renuncio a cualquier derecho patrimonial que se pueda generar por el uso de esta grabación.

He leido el presente documento antes de firmarlo y garantizo que comprendo el contenido del mismo. Se firma el día_______del mes de ________________de 20___.

Atentamente,

____________________________ ____________________________
NOMBRE FIRMA

C.C.____________________

Para compartir el video conmigo, debe enviarlo a mi whatsapp ______________

o mi dirección de correo eletrónico__________________________

Digital Storytelling information sheet and first consent form

Using Digital Storytelling to explore healthcare access among caregivers of children with Congenital Zika Syndrome in Colombia

Information sheet and Consent form: Digital Storytelling (Caregivers)

We are inviting you to take part in a research study. Before you decide whether or not to participate, it is important that you know why we are doing the study and what is involved. Please read the following information carefully.

What is the study?

- We are developing digital stories (2-5 mins videos) with caregivers of children with Congenital Zika Syndrome in Cali on their experiences receiving primary healthcare services. We aim to understand the digital story making process.

What will happen to the results of the research study?

- We hope to publish the results in a peer-reviewed article.
- Findings will be fed back to other researchers using or intending to use this method.
- If you consent (please refer to image consent form), digital stories will be used as a dissemination method to spread awareness on access to healthcare among children with disabilities in Colombia.

Do I have to take part?

- No, it is up to you to decide whether to take part. There will be no repercussions if you do not participate and no inference will be drawn from you not wanting to participate.

What will happen if I take part?

- If you decide to participate, we will explain about the digital storytelling process and the study.
- If you are happy to participate, you will be given the choice to fill in the consent form below before the online focus group or consent verbally before the beginning of the focus group. We will set up an online focus group discussion with all caregivers who will be taking part to discuss their experience in accessing healthcare for their children with Congenital Zika Syndrome.
- You are free to answer any discussion topic you want and we can skip any topic you would prefer not to answer.
- After the online focus group (approximately one hour and a half), we will have an individual discussion (via Zoom or Whatsapp) about how we can build your access to health story through a digital story. A digital story is a 2-5 mins video with voice over

and images/videos of your choice. You will decide what aspect of your healthcare access story is the most important and what to focus your digital story on.

- I can work through some examples with you. We will also define if you would like to show your face in the videos/photos and, if not, how we can blur or film/photograph without showing your face. After discussing the digital story, we can start compiling videos/photos and, depending on how long it takes, continue on another day.
- You will decide when the film is ready and when it tells the story you would like to tell.
- We will then set up an individual interview via Zoom, to discuss your thoughts on your film and the digital storytelling making process. With your consent, we will record the interview and transcribe for analysis.
- Additionally, with your consent, the film you made may be shown in screenings to help others understand the perspectives of access to healthcare for children with Congenital Zika Syndrome in Cali. This includes:
    - As part of this study report on the use of digital stories
    - In other reports, campaigns and publications by LSHTM or affiliated partners and donors
    - In university seminars and classes
    - At public exhibitions related to this study
    - On the LSHTM website
    - In media about this study
    - In social media (twitter etc)
    - In film festivals
    - This is completely voluntary, and you can specify whether you are willing for the film to be shown in each of these ways. If you do not want us to use the film, you do not need to explain why and we will not use it. This will not affect any future support or care that you might get. You will own the copyright on the digital images. This means that you have the right to say how they will be used. It also means that when they are used you will be always acknowledged as the producer of the film.

What will happen if I don’t want to carry on with the study?

- You can withdraw from the study during the digital story process, after the process and just before your quotes have been published in a paper by informing one of the researchers listed below or the researcher conducting your interview.

What are the alternatives?

- You could recommend this study to a person who might be interested in participating.
- We can start the interview or making the digital story and, if you see it is not something you want to take part in, we can stop at any moment and the data collected from you will not be used.
- You do not have to take part.

What are the possible benefits of taking part?

- There is no direct benefit from taking part in the interview, but we hope that it will contribute to disseminate information on healthcare access and improve the understanding of the use of Digital Storytelling.

Will my taking part in this study be kept anonymous?

- As we will be using videos, photos and voiceover, there is a high chance that you will be identifiable. If you choose to take part in the process, we can discuss the level of anonymity that you would like: Include photos/videos of yourself in an identifiable way, blur your photos/videos, use your original voice or add a masking effect to your voice, or only include videos/photos where you are not featured.
- For the interview, your comments will be identified by a research number only and we will not use your name. If there is something that you want to tell use that is particularly confidential/sensitive and you want to be certain that it is not attributed to you in anyway please let us know and we will ensure full anonymity.
  .

Who is organising the research?

- The study is being run by the London School of Hygiene and Tropical Medicine.

Who can I contact for more information or future updates?

Veronika Reichenberger
veronika.reichenberger@lshtm.ac.uk

Consent for taking part in a study on the use of Digital Storytelling to explore healthcare access among caregivers of children with Congenital Zika Syndrome in Colombia.

I ____ (name) confirm that I understand:

- What is required from me if I take part and understand that I will get no direct benefit from participating
- That my name will not be used
- I consent voluntarily to take part in the study and understand that I can withdraw at any time
- I consent to taking part in both the focus group on my child's healthcare access and the individual interview on Digital Storytelling
- I understand there is another consent form referring to image and video use

I am happy for the researcher to audio record our talk for the purpose of improving the accurately of reporting what was said only:

Yes ☐ No ☐

Signature:…………………………………… Date………………

Researcher

I ……………………………(name) confirm that I have carefully explained the nature and demands of the proposed research to the participant.

Signed:…………………………………….…..Date:………………………

Example Digital Storytelling second consent form – same used for Participatory Video

IMAGE CONSENT FORM

LONDON
SCHOOL of
HYGIENE
&TROPICAL
MEDICINE

PARTICIPANT TO COMPLETE:

I ………………………………………………………. understand that I retain copyright of my film but give permission for LSHTM to retain copies of the digital story and any photos taken in the process for use as consented to in the list below:

CONSENT CHECKLIST

I am happy for LSHTM to use my photographs and digital story in the following ways:	**YES** ☑	**NO** ☒
As part of this study report		
In other reports, campaigns and publications by LSHTM or affiliated partners and donors		
In university seminars and classes		
At public exhibitions related to this study		
On the LSHTM website		
In media about this study		
In social media (twitter, etc)		
In film festivals related to health, human rights and/or disability		

Do you want the film to be credited with your real name? **YES / NO**

If no please specify alternative name to be used……………………………………………….

Appendix 4. Supporting information for Paper Four

Information sheet and first consent form (Portuguese)

Explorar o acesso a serviços de saúde de pessoas com deficiência em Pernambuco

Método Vídeo Participativo

Objetivo:
Usar o método de Vídeo Participativo para explorar acesso a serviços básicos de saúde de pessoas com deficiência em Pernambuco.

Valor do projeto:
Tem crescido na literatura a importância de incluir pessoas com deficiência em pesquisas sobre eles próprios, através do uso de metodologias participativas. Essa tendência na literatura acompanha o lema do Movimento dos Direitos das Pessoas com Deficiência "Nada sobre nós, sem nós" exige a inclusão de pessoas com deficiência na pesquisa, como "especialistas por experiência" no campo. A abordagem baseada nos direitos humanos afirma que a participação plena é um direito humano que pode e deve ser reivindicado por todos. As pessoas com deficiência devem ser valorizadas como contribuintes essenciais para todos os setores, indústrias e comunidades em todo o mundo.
Certos métodos, como fotografia participativa (ou *photovoice*) têm predominado entre os métodos participativos e têm se mostrado especialmente importante, devido à sua natureza inclusiva de co-pesquisa, que aborda a exclusão e o estigma. Pessoas com deficiência têm a experiência do estigma em muitas áreas da vida, inclusive em pesquisa. O objetivo desse projeto é explorar o uso de Vídeo Participativo na pesquisa sobre deficiência global e preencher uma lacuna que existe do uso desse método em pesquisa sobre deficiência. Essa é uma metodologia amplamente utilizada para permitir que indivíduos explorem e contam suas próprias histórias sobre um devido tema. É especialmente importante entre pessoas marginalizadas, que podem então disseminar suas próprias descobertas através de filmes produzidos.

Metodologia:
Durante quatro dias os participantes explorarão a pergunta: “Quais são as barreiras e facilitadores do meu acesso a serviços básicos de saúde?” e, com a ajuda de um facilitador com treinamento em vídeo participativo, ele/ela será apoiado a responder a essa pergunta com o uso de fotografias e vídeos registrados no passado, fotografias e vídeos coletados no presente, e a montagem de um vídeo contando sua história. Uma vez que todas as fotos e vídeos forem coletadas, esses serão examinadas em um ambiente de entrevista com os participantes, onde eles explicarão seu acesso a serviços com a ajuda dos materiais visuais.
As entrevistas serão gravadas, transcritas, e codificadas, com o uso do Nvivo. A análise fenomenológica interpretativa será usada para analisar as entrevistas e fotos/vídeos, para explorar tanto os temas pré-concebidos como os recém surgidos.

As fotos e vídeos serão editadas em um filme com a ajuda do facilitador, usando o programa Final Cut Pro X. Os filmes serão divulgados para engajamento do público, nas áreas consentidas pelos participantes.

Número de participantes e justificativa:
Um total de 12 pessoas será propositadamente amostradas a partir do estudo qualitativo mais amplo, com os principais critérios de interesse em fotografia ou vídeo. O número de participantes foi escolhido como um número viável para alcançar a profundidade da análise de dados e garantir a qualidade do trabalho dentro do prazo do projeto. As pessoas com deficiência serão selecionadas para representar uma variedade de tipos de deficiência para que se inclua uma amostra ampla dentro do subgrupo.

Consentimento:
O projeto será analisado por um Comitê de Ética em Pesquisas com Seres Humanos e foi elaborado e será executado de acordo com as diretrizes constantes das Resoluções CNS 466/2012 e 510/2016. Também será incluída uma fase de devolutiva dos resultados, uma vez que os participantes serão usuários do Sistema Único de Saúde, conforme normativas da Resolução CNS 580/2018.
O consentimento informado será solicitado no início do desenvolvimento do projeto e incluirá a o treinamento, a coleta de dados e a entrevista. Isso envolverá a explicação sobre o projeto, informação sobre riscos e benefícios da participação, os direitos dos participantes (por exemplo, direito de retirada do consentimento em qualquer momento sem prejuízo para seu tratamento, proteção dos dados), os contatos da pesquisadora e do CEP onde a pesquisa foi analisada. Os participantes também serão informados da possibilidade de uso dos vídeos para divulgação. As explicações sobre a pesquisa e consentimento serão conduzidos por pesquisadores treinados. Para indivíduos com deficiência auditiva profunda, será disponibilizado um intérprete de língua de sinais. Se um participante não puder se comunicar de forma independente ou solicitar a presença de seu cuidador, os cuidadores serão convidados a participar do treinamento e da entrevista, e serão os responsáveis pelo consentimento, uma vez que o assentimento seja dado pelo participante.
Após a apresentação e aceite em participar, os participantes serão convidados a assinar um Termo de Consentimento Livre e Esclarecido.

Desconforto e risco:
Os riscos com a pesquisa são pequenos, sendo que os participantes podem se sentir desconfortáveis durante a oficina de produção dos vídeos e durante a entrevista, ao recordar acontecimentos marcados por dificuldades e preconceitos. No entanto, lhes é assegurado o direito de se recusar a responder quaisquer perguntas, ou mesmo retirar seu consentimento em qualquer etapa da pesquisa, sem nenhum prejuízo para seu atendimento.
Se, durante o processo de entrevista, identificarmos os participantes que necessitam de serviços de saúde imediatos, eles serão encaminhados a profissionais de saúde locais para facilitar o acesso a serviços apropriados imediatamente.
Os participantes serão claramente informados sobre como os filmes serão usados e serão convidados a dar consentimento sobre como eles serão usados. Lhes é garantida a liberdade de não consentir sobre o uso do filme para divulgação.

Os participantes também serão informados sobre o fato de que o uso de fotografia e vídeo pode facilitar a identificação deles. Se o participante concordar em participar, trabalhemos juntos a ele/ela para garantir o nível de anonimato que eles quiserem (não incluir fotos/vídeos deles, usar um pseudônimo, borrar qualquer aspecto no vídeo ou foto que possa identifica-los).

Consentimento

Eu ____ (nome) concordo em participar e entendo:

- O que acontecerá durante o processo
- Eu dou meu consentimento voluntário para participar do estudo e entendo que posso sair e parar de participar a qualquer momento.
- Terá uma outra folha de consentimento especificando a disseminação do uso das minhas imagens e vídeos.

Sim ☐ Não ☐

Assinatura:……………………………………… Data………………

Second consent form (Portuguese)

Explorar o acesso a serviços de saúde de pessoas com deficiência em Pernambuco
Termo de Autorização de Uso de Imagem

Este formulário deve ser assinado pela pessoa que concordou em participar da pesquisa "Explorar o acesso a serviços de saúde de pessoas com deficiência em Pernambuco." Este estudo está sendo realizado pela Fiocruz e conta com a colaboração da Faculdade de Medicina da Universidade de São Paulo (FMUSP) e da London School of Hygiene and Tropical Medicine (LSHTM).

Assinando abaixo, eu confirmo que entendo que os direitos autorais e propriedade intelectual dos vídeos criados pertencem a pesquisadora principal do projeto Veronika Reichenberger.

Eu concordo que a FMUSP e organizações colaboradoras usem o meu filme das seguintes maneiras:	**SIM** ☑	**NÃO** ☒
Como parte deste relatório de estudo		
Em outros relatórios, campanhas e publicações da FMUSP, LSHTM, Fiocruz ou parceiros afiliados e doadores		
Em eventos públicos relacionados a este estudo		
No site da FIOCRUZ		
No site da LSHTM		
No site da FMUSP		
Em mídia sobre este estudo		
Em redes socias (twitter, etc)		

Você quer que o filme inclua o seu nome verdadeiro como produtor? **SIM / NÃO**

Se a resposta for não, qual alternativa você gostaria que usemos…………………………………………....………..

POR FAVOR PREENCHA OS SEUS DETALHES ABAIXO:

Nome completo do participante:

Número de telefone celular do participante (se houver):

E-mail do participante (se houver):

Assinatura:

Nome	Data	Assinatura