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Editorial

Challenges and Opportunities in Disability-Inclusive Development

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Dear Readers,

It is with great pleasure that we welcome you to read Volume 36, Issue 2 of the Disability, CBR and Inclusive Development Journal. As a platform dedicated to amplifying voices, lived experiences, and research that inform inclusive practices, we are proud to present a rich collection of seven insightful articles that engage deeply with the challenges and opportunities in disability-inclusive development across diverse contexts.

This issue begins with a powerful and eye-opening piece by Thulile Duma that brings us into the everyday experiences of students with dwarfism in higher education. Through the voices of two young women, we see how something as simple as a classroom chair or reaching a door can become a daily challenge, reminding us that many university spaces are still not built with everybody in mind. Grounded in social justice and universal design principles, the article doesn't just highlight the problems; it calls on all of us, educators, planners, and institutions, to do better. It's a timely and necessary reminder that true inclusion means creating environments where everyone, regardless of their body size, can learn with dignity and comfort.

Our second article takes us to rural South India, where a cross-sectional survey examines the functional independence, quality of life, and level of community participation of stroke survivors, as well as the burden experienced by their caregivers. The study reveals moderate levels of independence but extremely limited community reintegration, alongside moderate to severe caregiver strain. The message is clear: recovery extends far beyond the clinical setting. There is a pressing need for comprehensive, community-based rehabilitation that restores not just function, but also hope, connection, and dignity.

Our third contribution highlights a Community-Based Rehabilitation (CBR) initiative in Santiago Atitlán, Guatemala, aimed at improving access to primary healthcare for people with disabilities. Set against a backdrop of cultural complexity, systemic barriers to healthcare, and traditional worldviews, this study explores the perspectives of the various stakeholders on a pilot project developed to improve access to primary healthcare for people with disabilities. It illustrates how partnerships between organizations of people with disabilities, public health services, and community members can foster more inclusive and culturally relevant healthcare. This study demonstrates that when local voices lead and community traditions are respected, sustainable change becomes possible.

In the fourth article, we gain insights from a qualitative study in Thailand examining the role of communication and information access for persons with disabilities during the COVID-19 pandemic. Through the lens of intrapersonal group, and mass communication, this research explores the role of communication in supporting persons with disabilities and their caregivers during crisis, separated into different levels of communication.

Despite significant barriers, especially in rural areas, informal networks, peer support, and digital tools became critical survival mechanisms. This study highlights the critical tensions between resilience and exclusion, and the necessity of inclusive, multi-level communication systems in emergency preparedness and response.

The fifth article in this issue, by Elizabeth N. and colleagues, shines a necessary light on the everyday realities of women with disabilities working in Malawi. Through honest and moving accounts from 45 women, the study reveals how discrimination, inaccessible workplaces, and deep-rooted gender inequality make it incredibly difficult for them to thrive. Yet, despite these barriers, the women show remarkable resilience, drawing strength from each other and finding ways to cope in environments not built for them. This piece is a powerful reminder that creating truly inclusive workplaces means listening to those most affected and acting on what they say.

Turning to education, a standout study from India explores strategies for fostering inclusive early childhood education for children with communication disorders. Based on the perspectives of over 170 rehabilitation professionals, the article highlights the critical importance of early intervention, teacher preparation, and cross-sectoral collaboration. With more than 85% of brain development occurring in the early childhood, ensuring that children with communication needs are supported from the outset is not only developmentally sound it is ethically essential.

The final article offers a narrative review from Indonesia, which focuses on the evolution of community-based cardiac rehabilitation (CBCR) in response to rising non-communicable diseases rates. The review outlines how community-based models such as Prolanis and Posbindu PTM promote cardiovascular health in resource-limited settings through education, prevention, and peer support. While challenges remain particularly in implementation and outreach, the paper presents an optimistic outlook for expanding affordable, culturally appropriate, and scalable community centred rehabilitation strategies.

Together, these seven articles offer rich, diverse, and action-oriented insights that contribute meaningfully to our collective understanding of inclusive development. Whether in health, education, community rehabilitation, or crisis response, each contribution reflects a shared call: to move beyond rhetoric and make inclusion a reality, through research, partnership, innovation, and persistent advocacy.

This issue would not be possible without the dedication of our authors, peer reviewers, and editorial team. We also extend special thanks to practitioners and researchers who continue to push boundaries and champion inclusive approaches in their communities while working in complex and resource-constrained settings.

To our readers, whether you are academics, students, policymakers, professionals, or advocates, we invite you to engage with this issue not just as readers but as partners in action. May these articles inspire reflection, spark dialogue, and inform your efforts to build systems and societies that leave no one behind.

With appreciation and solidarity,

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Original Research Article

Experiences of Dwarfism in Higher Education Learning Environment in South Africa

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ABSTRACT

Background: Students with short body stature, such as those with dwarfism, not only find it difficult to access higher education institutions, but also experience physical and psycho-emotional trauma. The experiences of accessibility and inclusivity in learning environments for students with dwarfism at a university of technology in South Africa premise this study.

Methodology: The study employed interpretative phenomenological analysis, which allowed the participants to share their lived experiences of dwarfism in relation to their learning environment in a higher education institution (HEI). The theoretical framework of Rawl's distributive justice, which promotes equitable distribution of social resources and universal design that emphasizes equal access to and use of goods and facilities, further supported this. Purposive sampling identified two female participants with dwarfism. An in-depth qualitative research design was used to collect data on the lived experiences of accessibility and inclusivity in the participant's learning environment. The phenomenological data analysis, which involves data bracketing and reduction methods, explicated the themes.

Findings: The findings revealed that the learning environment for students with dwarfism is in contradiction with universal design and social justice principles. Such an environment is detrimental to their health, quality epistemic access, self-esteem, and academic performance.

Conclusion: The findings of this study will be instrumental for developing and designing a universal learning environment. Failure to provide learning environments that adhere to universal design and social justice principles is tantamount to discrimination and the violation of the basic human rights of minority groups.

Keywords: learning environment, dwarfism, social justice, inclusivity, universal design

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INTRODUCTION

The goal of this study is to evaluate the accessibility of the learning environment for students with dwarfism in higher education institutions. People with dwarfism are considered a minority group, with one individual out of 25,000 people affected by this condition (Pritchard, 2021; Zuinudin et al., 2019; Ktenidis, 2022). Approximately 652,000 individuals live with this condition worldwide. Dwarfism, also known as skeletal dysplasia, is a group of conditions caused mainly by a genetic mutation or an inherited genetic change characterised by shorter than normal skeletal growth that manifests in the legs, arms or trunk, resulting in exceptionally small body stature (Pritchard, 2016; Pritchard, 2021). It is common for such people to experience other physical challenges such as reduced muscle tone and strength, breathing problems, curvature of the spine (or spinal stenosis), bowed legs, limited joint flexibility (arthritis), lower back pain and leg numbness (Mohammad, Mohammed & Mandegari, 2015). Pritchard (2021), who lives with this condition, argues that most people living with dwarfism have an average body stature of 147 cm.

The dwarfism phenomenon is often associated with the medical model of disability, which suggests that the disability should be medically treated (Shakespeare, Thompson &Wright, 2010). While the medical model of disability cannot be ignored, the social model proposes the provision of a socially just, easily and equally accessible, non-discriminatory as well as enabling environment for people with impairments and non-impairment (Duma, 2019). Most people with physical disabilities, particularly those with dwarfism spend at least 90% of their day trying to gain access in social unjust environments (Mohammad et al., 2015). Their condition is sometimes confused with that of people who use wheelchairs for movement (Mohammad et al., 2015; Pritchard, 2016), in terms of accessible environment. Different countries refer to this type of disability under different names to avoid insulting people with dwarfism. While, in most European countries, they are referred to as "little people" or "people with limited growth," in African countries, they are referred to as "dwarfs" (Ktenidis, 2022). None of these labels respect their condition as it is a constant reminder of their condition.

Furthermore, people with short body stature are sometimes abused and face a lack of justice when they are used as money-making entertainment figures- an experience that many find humiliating (Bourmans, 2019; Pritchard, 2017). According to Pritchard (2016, 2021), many people with dwarfism face social injustices and exclusion since social environments and facilities are designed for people of average height. This often leads to dependency and frustration because they are forced to seek alternatives if no one is willing to assist them (Zanuid et al, 2019). Ktenidis (2022) contends that students with dwarfism in higher education are more susceptible to violence and bullying. Owing to their diminutive size, they frequently fall prey to maltreatment and dehumanisation, and their rights are predominantly violated.

Accessibility in higher education institutions

Accessibility in higher education institutions (HEIs) for students with disabilities is gradually receiving positive attention (Duma, 2019; Duma & Shawa, 2019; Mosia & Phasha, 2020). Conversely, there seems to be meagre studies on accessibility of learning environments for students with dwarfism in the South African context. Despite the increasing number of students with disabilities enrolled for tertiary education, the lack of enabling environments for students with dwarfism emphasises and necessitates the responsibility of HEIs to accommodate the diverse needs of all their students. This automatically prescribes the direction of change and transformation in terms of policies, practices and learning environments of HEIs (Mugambi, 2017). Globally, HEIs have many traces of ableism in their practices, policies, culture, and infrastructure (Pritchard, 2016; Dolmage, 2017; Evans, 2021) in terms of spatial distributive justice for students with disabilities. This is sufficient evidence that HEIs were designed to cater for 'healthy' and able-bodied students, thereby excluding people with disabilities (Evans, 2021; Mutanga, 2017).

Goal 4 of the 2030 Agenda for Sustainable Development (United Nations, 2015) has increased the responsibilities of HEIs, mandating them to ensure inclusivity and equitable quality education through social inclusion. HEIs are seen as "houses of knowledge" and "houses of transformation," tasked with the dissemination of knowledge and fostering change (Purcell, 2019; El-Jardali, 2018; Brunner & Labraña, 2020), hence necessitating an expectation of equality and a non-discriminatory atmosphere. Students expect equal and fair treatment while seeking the tools (qualifications) to combat global poverty, unemployment, inequality, and injustice of the world. If access to education is a fundamental human right, creating an equitable learning environment should not be a challenge.

The right to accessibility and inclusivity for people with disabilities is entrenched in varying pieces of legislation such as, the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (United Nations, 2006) and in the South African White Paper on the Rights of People with [a] Disability (Department of Social Development, 2015). The South African Constitution, as per Section 29 (1), Section 2 and Section 9 (3), advocates for the basic human rights of people with disabilities and the provision of an inclusive and conducive environment (RSA, 1996). The purpose of this paper is, therefore, to examine the experiences of accessibility and inclusivity of learning environments for students with dwarfism at a university of technology in South Africa. The findings aim to bring new knowledge and suggestions for improving social justice in higher learning environments.

Objective of the study

The objective of this study is to critically evaluate the inclusivity of tertiary educational institutions for individuals with dwarfism through the analytical social justice framework and universal design.

Theoretical framework

Social justice

The study is premised on Rawls' theory of social justice, which seeks to promote a fair and equitable distribution of power, resources, access, and opportunities (Rawls, 2020). This theory acknowledges that deeply entrenched inequalities exist in societies where minority needs are disregarded (Sabbagh & Schmitt, 2016). Injustices continue to negatively impact students with disabilities in higher education settings, yet untransformed institutions continue to admit such students (Matshediso, 2010). While policies addressing the rights and needs of people with disabilities are often in place, the implementation of these policies has been remiss, resulting in a lack of enforcement and sanctions for non-compliance thereof (Matshedisho, 2010; Mutanga, 2017). To address these deficiencies, Rawls' social justice theory calls for retributive and distributive justice for minorities and vulnerable groups (Sabbagh & Schmitt, 2016). Retributive justice aims to rectify injustices by restoring equality and removing barriers, while distributive justice advocates for the equal distribution of benefits and the protection of the vulnerable.

Universal design

Providing an accessible and user-friendly physical-built environment with no barriers should not only be associated with people with disabilities, rather it must be a standard norm (Dalton, Lyner-Cleophas, Ferguson & McKenzie, 2019). Denying people access to such environments is tantamount to discrimination and exclusion and is against the constitution of the country which advocate for equity. The universal design (UD) concept focuses on engineering and architectural designs that intend to cater for the diverse needs of society (Burgstahler, 2008). UD expounds seven principles that can be applied to both public and private environments, and whose products, services, infrastructure, furniture and facilities should provide inclusive and equal access to all (Center for Universal Design, 2008). These are:

- ***Equitable use***: The design should not only be useful to people with diverse abilities but must also provide the same means of use for all users.

- ***Flexibility of use***: The design should accommodate a wide range of individual preferences and abilities. It also includes choices in methods of use, facilitate the user's accuracy and precision, and provide adaptability to the user's pace.
- ***Simplicity and intuitive***: Regardless of the user's experience, expertise, language skills, or present focus level, the design should be simple to use.
- ***Perceptible information***: The design should communicate necessary information effectively to the user, regardless of ambient conditions or the user's sensory abilities.
- ***Tolerance for error***: The design should minimize hazards and adverse consequences of accidental or unintended actions.
- ***Low-level physical effort***: Allow for a reasonable effort on the part of the user, accommodate variations in hand and grip size, and minimize sustained physical effort.
- ***Appropriate size and space for approach and use***: Regardless of the user's body size, posture, or mobility, the necessary size and space should be supplied for approach, reach, manipulation, and use. All potential users' reach and manipulation needs should be considered.

UD principles are critical in providing a conducive, inclusive, and equitable learning environment suitable for both students and staff. Dalton *et al.,* (2019) argue that UD principles should be considered in the establishment of enabling learning environments to provide access for all regardless of ability and disability.

According to Moriña & Morgado (2018), architectural and infrastructural barriers continue to exist at many HEIs across the globe. Research in the current HEIs environment expostulates that many university buildings and teaching and learning facilities do not meet ergonomic standards, especially for people of alternate body sizes (Pritchard, 2021; Khumalo, 2020). Physical facilities and furniture are frequently designed with only the ergonomic principle of an 'average-sized person' in mind (Uche & Okata, 2015; Pritchard, 2021). Ntombela (2020) highlighted the persisting challenge of the inaccessibility of learning environments experienced by students with disabilities due to discriminatory architectural designs in HEIs. According to Uche and Okata (2015), the teaching and learning environment in HEIs "...must be designed in such a way that it matches the capabilities, limitations and needs of the users" (p. 34). Parvez, Parvin, Shahriar & Kibria, (2018) concur and recommend that furniture and equipment within the learning environment should adhere to anthropometric principles. This means that it should be designed for:

- all body sizes which could range between 5th and 95th percentile; and
- average, more common body sizes and postures.

The absence of ergonomic considerations in such designs has a direct impact on the level of comfort that educators and students of all body sizes and abilities experience in their quest to achieve their educational objectives. For instance, the appropriate posture requirement design of chairs and desks is important if teaching and learning is to occur equally for all students in the classrooms, offices, laboratories, libraries, and residences or wherever they are accommodated. The design of furniture should thus consider anthropometry, which refers to the dimensions of the body in terms of body size, shape, strength and capacity (Uche & Okata, 2015; Parvez et al., 2018). In order to examine the social fairness and accessibility of the learning environment for students with short body stature, this study will apply four UD principles, which are: i) equitable use, ii) flexibility in use, iii) low-level physical effort, iv) appropriateness and space for approach and use.

METHODS

Study Setting

The ultimate goal of this study is to evaluate the accessibility of HEIs for students with dwarfism; thus, the study is conducted in a historically disadvantaged institution (HDI) in South Africa. Such institutions continue to struggle with providing basic facilities, not only for students with disabilities but also for all students and staff (Ayuk & Koma, 2019).

Research approach and design

This interpretative phenomenological analysis (IPA) study aims to evaluate the fundamental and invariant components of the participants' lived experience of dwarfism in relation to the accessibility of their learning environment. IPA research is mostly suitable for exploring uncommon, sensitive, and personal experiences. When participants offer a comprehensive narrative of their experience with the phenomenon, these accounts may explore emotions, convictions, attitudes, perceptions, and cultural influences. Consequently, the data generated is exclusively qualitative and non-numerical, as the participants provide a profound comprehension of the occurrence (Greening, 2019). The analytical framework used in this study–IPA-, as described by Alhazimi and Kaufmann (2022), which integrates descriptive and interpretative phenomenology, forms the basis of the study. Bracketing is essential in phenomenological studies to mitigate bias and ensure the authenticity and reliability of the research (Greening, 2019).

Sample Size

Determining the sample size for IPA studies may come with challenges as participants could not always be willing to talk about their experiences where the case is sensitive (Subedi, 2021). According to Alase (2017, p.13), “in a phenomenological research tradition, the size of the participants can be between 2 and 25.” Disability is quite a sensitive issue and dwarfism is a rare condition. There are only two registered female students with this impairment in this institution. People with dwarfism are a minority, with approximately 652,000 individuals worldwide living with this condition (Warwick, n.d.; Pritchard, 2021; Ktenidis, 2022). There are approximately 55 registered students with disabilities in this institution. Thus, a purposive sampling was employed (Alhazimi & Kaufmann, 2022).

Data Collection

A 30-minute in-depth interview with each participant was done after gaining consent for participation from each student. Interviews were held in a classroom setting (but not during class hours), allowing participants to exhibit some of the accessibility challenges they face in their learning environment. The interview questions were developed based on four UD principles, which are: equitable use, flexibility in use, low-level physical effort, appropriateness, and space for approach and use as well as of social justice. The following questions were structured from the UD principles and social justice to guide the interviews:

- Equitable use: In what ways does this design ensure fairness and accessibility for diverse users?
- Flexibility of use: How does the design enable people with varying abilities to use it in multiple ways?
- Low-level physical Effort: How does this design minimize the physical effort required for use?
- Appropriateness space for approach and use: How can people of varying sizes and abilities use this design to meet their specific needs?
- Social justice: How equitable is the learning environment equitable to all users?
- These principles are more concerned with physical access and equitable use of the learning environment to all users regardless of their body stature, which is the focus of the study.

Procedure and Ethics Approval

The researcher followed the research ethics procedures set by the institution, and ethical clearance was granted to continue with the study (ref RD1/09/022). Conducting research involving minority and vulnerable groups comes with some restrictions because they need to be protected against any form of abuse and exploitation. The institution where the study was conducted does not yet have a disability unit, thus the student counselling unit was requested to be present to provide guidance on how to approach the participants. Furthermore, to protect the identity of the two participants, pseudonyms, 'Queen' and 'Joy' were used in accordance with the Protection of Information Act 4 of 2013.

Data Analysis

Husserl, Giorgi, and Heidegger, the pioneers of phenomenology, argued that the essence of phenomenology lies in descriptive phenomenology and interpretative phenomenology, which enable others to understand the experience of a phenomenon (Alhazmi & Kaufmann 2022; Thonhauser, 2023). The analysis of IPA data is quite rigorous and intense, especially considering the complexity of the phenomenon. I followed the data analysis steps, which include transcription, initial coding, categorization, and up to the final stage of producing themes. Qualitative data analysis may be similar; however, IPA data analysis requires bracketing and reduction (reduction is the process of re-describing and explicating meaning from the described experience). Researchers can achieve this by distancing themselves from the research to establish credibility and trustworthiness.

Alhazmi & Kaufmann (2022) define data analysis as a process that involves explicating meaning and themes from the thick texture of lived experiences to form a formidable structure. "Researchers adopting these perspectives 'borrow' the participants' experience and their reflections on their experience to get a deeper understanding and to grasp the deeper meaning of the investigated experience" (Alhazmi &Kaufmann, 2022, p.2). The phenomenological reduction as explicated in Moustakas (1994) deals with the texture (raw data as experienced) and structure (themes as understood by the researcher). This kind of analysis puts more emphasis on 'horizontalization of data' (developing meaning units for each participant's experience) (Alihazimi & Kaufmann, 2022), which assisted me in familiarising myself with data coding and identifying and interpreting themes (Moustakas, 1994; Alase, 2017; Van Manen, 2017; Alhazimi & Kaufmann, 2022). The thoroughness of the IPA method ascertains the trustworthiness, credibility, and transferability of the study as the researcher continually engages with the data to get its essence (Loh, 2013; Korstjens & Moser 2018; Stahl & King, 2020).

RESULTS AND DISCUSSION

The participants expressed their frustration with their learning environment, which is riddled with a disregard for UD, social justice, the social model, and inclusive education principles. They reported difficulties in accessing various university facilities due to their small body stature. Four themes were derived from the data analysis: inequitable access to facilities, discomfort, and negative impact on academic work, and preference of online learning.

The principles espoused by the concepts of inclusive education, social justice, and UD are inextricably linked, as they all advocate for equal access and full participation within HEIs (Mugambi, 2017). Any learning institution's primary responsibility is to ensure an equitable learning environment by eliminating systematic barriers. When this mandate becomes visible, it is a significant indication that the institution recognises all its students' human rights (Dalton et al., 2019).

Inequitable access to facilities

Participants' descriptions of their learning environment revealed issues such as limited accessibility and inappropriate facility and furniture. The findings revealed that university infrastructure and facilities are not equitable and flexible to students with small body stature. Queen stated:

> *"Our disability is different and difficult. We need special accommodations in terms of furniture and other facilities. This makes life difficult because when you look around, there are very few who have this condition. It makes me feel this will never improve because institutions will not change their structures and systems for a few people".*

Being denied access has far reaching consequences, which may leave students with a state of helplessness, dejection and left behind, which could negatively affect their academic progression and could result in low self-esteem. Joy shared the same sentiments:

> *"My body size [dwarfism] and challenges we encounter seem not important or unnoticed. There is no furniture in the university that is designed to suit my needs [i.e., for dwarfism] and it is difficult to sit still in classrooms for two hours…Circumstances force us to be strong, find ways of coping and focus on our academic work".*

A mismatch between students' anthropometric dimensions and the dimensions of the furniture can also have a negative impact on their health and performance (Burgstahler, 2008; Mohammad et al., 2015; Mogendorff, 2017). According to Fredwall et al. (2019), this incompatibility has a potential of causing a reduction in efficiency, early fatigue, and cervical, backbone and lumbar pain. Furthermore, it can be responsible for postural disorders such as scoliosis and lordosis after long-term use. This is also in line with Uche & Okata (2015) and Pritchard (2021) findings that the furniture provided in learning environments should be ergonomically and anthropometrically designed to accommodate all users.

Adherence to social justice and universal design are critical for inclusive education, which acknowledges the needs of all users regardless of their size and height. Likewise, they are central to both anthropometric and ergonomic principles. This study found that equitable use is highly disregarded in this institution, which has an adverse impact on students with short body stature.

Discomfort

Rigidity in the learning environment or tools denies students access and cause unnecessary frustration. Infrastructure and facilities that are not inclusive and flexible to all users make students dependent, reducing their self-confidence and self-esteem. Facilities should be flexible to accommodate the diverse needs of users, especially in public spaces like in HEIs. Queen and Joy did not appear to fit in any space in their learning environment, and that created frustration and a feeling of being a misfit. Queen stated:

> *"The learning environment is quite frustrating for me. There is no space where I fit comfortably. I do not know how many times in a day I ask for assistance from others simply because I cannot reach something."*

Joy further explained:

> *"You know as students; it is not always nice to sit on the front row. However, for us, it's different. We do not have a choice but to sit there. It means you need to rush to class for you to get that front seat. Otherwise, it is a struggle to see the board and the lecturer… view is blocked".*

The furniture design does not accommodate students with dwarfism, causing discomfort and embarrassment. People with short stature experience such feelings not only in HEIs but even in supermarkets or public spaces, as discussed by Pritchard (2016).

Queen still remembers an awkward experience that took place in her learning environment.

> *"I once fell off from a highchair in the library by the newspaper section while I was trying to sit properly; I was very embarrassed".*

Their learning environment not only makes them feel excluded, but it is also harmful to their health, and these circumstances have an impact on their academic performance. Joy mentioned that she used to skip classes because she felt so uncomfortable.

> *"It is even worse to attend three classes in a row. Our classroom seats are high for my height and they are slippery. My feet hang and they get swollen after sometime, My feet normally feel numb after hanging at least for three hours. That is why I cannot attend many classes in a day".*

Furthermore, Joy is concerned that infrastructure challenges are almost everywhere; there is no space within the campus where she finds herself completely comfortable. Students with dwarfism constantly need to make an effort for them to get access.

> *"A simple thing like opening a door is often a problem more especially with load shedding* [1] *because the automated doors do not work when there is no electricity. Then you need to push them very hard because they are heavy. Even where we need to swipe our student cards, it is way up there... Think of notice boards: they are all up there! I rely on others to read [notices] to me. This takes away my freedom and it is not nice to rely on other people all the time."*

They encounter similar challenges in residence. Queen said:

> *"To survive in a residence, one has to rely on friends and roommates for many things, like opening a window. I cannot reach the windows... I remember one evening it was raining, and I had to ask someone to come and close the windows for me. It is not nice to be so dependent."*

It is unacceptable to put students in such state where their dignity is compromised. This could even affect their self-confidence as well as academic performance. Research in the current HEI environment suggests that many university buildings and teaching and learning facilities do not meet ergonomic standards, especially for people of extreme body sizes (Pritchard, 2021). Physical facilities and furniture are frequently designed with the ergonomic principle of an 'averaged-sized person' in mind (Uche & Okata, 2015; Pritchard, 2021). Ergonomic considerations should be the determiners in the design of buildings and facilities as they impact the level of comfort that educators and students of all body sizes and abilities experience in their quest to achieve their educational objectives. The appropriate posture design of chairs and desks (or any facilities in public spaces) is important in achieving inclusive education.

The design of furniture should thus consider anthropometry, which refers to the dimensions of the body in terms of body size, shape, strength and capacity (Uche & Okata, 2015; Parvez et al., 2018).

Inappropriate size and space causes dependence

Universities are not only social spaces, but also knowledge spaces with the potential to develop and transform people's lives. They are competitive educational organisations that facilitate the attainment of qualifications that can lead to financial independence (Parvez et al., 2018; Rutherford, 2015; Pritchard, 2016; Nyamupangedengu, 2017). According to Sabbagh (2016), for universities to be "just learning spaces," distributive justice must prevail. Minority and disadvantaged groups qualify for fair and equal access to resources

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[1] In South African context, load shedding is an energy utility method of reducing demand on the energy generation system by temporarily switching off the distribution of energy to certain geographical areas.

and success. Discussions about spatial accessibility and inclusivity are incomplete unless universal design is part of them. Similarly, social justice and social inclusion may not prevail if such facilities are not universally designed.

However, the inappropriate and unfriendly learning environment of this institution has made these participants reconsider their class attendance. Queen opted for evening classes to ameliorate the situation, which was affecting her health.

> *"Since I am a third-year student, I decided to shift to evening classes, which comprise two lessons from 16:30 to 20:30; this is much better than the day classes that commence from 8:20 to 14:20. Assessment time has its own challenges. Most papers are 2 hours long and 3 hours for examination. By the end of the paper, my feet are solen due to hanging for a long time."*

Paying attention and fully participating in class is not easy. Joy also narrated that a simple activity like taking notes in class becomes a challenge:

> *"The space in between the seat and the tabletop is too wide for me to reach. After sitting for some time, my lower back and spine become painful. If I lean back, I cannot reach the top of the table. This means that when I write, it is better to hold my writing pad on my lap rather than put it on the table. Nothing is easy or comfortable in class. Therefore, paying attention to the lecturer is not easy because I spend most of the time adjusting my sitting position. My academic work is affected."*

Due to challenges in their learning spaces, students with disabilities are becoming techno savvy and gaining confidence with technology. Queen alluded to the difficulties in the library and prefers online material:

> *"The main challenge in the library is the height of the bookshelves. It means I must always have someone to assist me. That part is annoying, and it takes away my independence. I am learning to rely on e-material."*

Such experiences make learning less enjoyable when they need to exert extra effort to access facilities, whereas according to the UD principles, there must be a low level of physical effort in accessing facilities. Students' performance may be adversely impacted and make them feel left behind when HEIs' infrastructure and facilities do not comply with the principles of UD as well as Rawls social justice. Universities are obligated to offer inclusive education, high-quality instruction, appropriate curriculum design, a welcoming and conducive learning environment, and appropriate assessments to meet the diverse needs of students (UNESCO-IESALC, 2020; Dalton et al., 2019; Department of Higher Education, 2018).

Preference of online learning

The study also found that there seems to be positive gesture towards online learning as the students do not need to be in contact with other students or with the frustrating infrastructure. COVID-19 introduced online learning, which was not easy to adapt due to several issues including data availability, network, compatible devices and assistive devices (Hanjarwati & Suprihatiningrum, 2020). Due to the infrastructure and resources available on campus, students with impairments preferred face-to-face learning (Duma & Chamane, 2023; Meda & Waghid, 2022). In contrast, this study discovered that students of short stature prefer online learning due to their learning environment's hostile and inadequately planned facilities and infrastructure.

COVID-19 gave students with short stature a relief from stigmatisation and frustration of attending face-to-face classes. Both students, Queen and Joy, are happy with online classes.

> *"I was very happy with online classes during COVID as there was no unnecessary attention on me. I attended online classes like any other student. I hope the university continues with this mode of conducting classes."*

In many instances, universities opt for designs that suit their budget and by so doing compromise the diverse needs of the users (Mutanga, 2017). Current theories and technologies require that teaching and learning environments should not only be comfortable, but also meet the physical and health needs of the users (Uche & Okata, 2015). The challenges of access are well captured by Nyamupangedengu (2017, p. 114), who argues:

The main educational challenge in these circumstances is not the diversity of the student body, [but] rather the failure by institutions and individuals to factor the standard teaching and learning process to the realities of the great majority of the current student body.

The general findings of this study discovered that the distributive justice and UD principles of equitable use, flexibility in use, low level physical effort as well as appropriateness and space for approach and use are highly compromised in this institution. Therefore, students with short body stature have limited access to their learning environment. This has an adverse impact on students' academic performance, self-confidence, and health. The non-compliance of HEIs with many of the policies on disabilities promulgated at national and international levels as well as their own (individual university policies) should come with a hefty penalty (Matshedisho, 2010).

Whilst punitive measure needs to be taken, the financial state of the institution could be limiting. According to Stanczak et al. (2023), compliance with UD principles and retributive justice are mandatory. Still, the actual application could be difficult, as universities may not have the financial muscles to create the enabling teaching and learning environment. For instance, this university is one of the previously disadvantaged universities located in the peripheries of the city and serving disadvantaged communities. Implementation of universal design and social justice-aligned learning spaces could be a challenge due to government-dwindling funding (Universities South Africa, 2017).

CONCLUSIONS

Issues of inclusivity and accessibility in public spaces as well as in higher education institutions remain critically important in making such places user-friendly and providing efficient services.

There should be no point where students feel their body stature is not acceptable in any learning environment. The social justice theory and UD principles have been used to understand the equitable allocation of learning spaces and facilities in an educational institution, as they underscore the necessity for inclusive and quality education as well as equality for minority groups.

HEIs should avoid ableism (Dolmage, 2017), which occurs when equity is implemented blindly and may not adequately address the diverse needs of students with rare disabilities. Many public spaces are wheelchair accessible but not body or height accessible. Transformation would be possible if social justice and universal design were treated as two sides of the same coin, and then inclusive education in HEIs would become a reality. Quality education has many implications, such as equal access to learning institutions and conducive learning environments where didactical and pedagogical principles favour the needs of diverse students.

HEIs should also realize that social justice and universal design principles, which guarantee that no student is left behind, can be used to achieve epistemic access, inclusivity, and equity. Since ubuntu fosters interpersonal caring, it is imperative that these values permeate HEIs. Any delay in engaging with dwarfism within the HEIs sphere may have dire consequences for improving epistemic access and success for students with dwarfism. Open dialogue, consultation, and feedback with the primary users should be taken into consideration in drawing improvement plans. It would be beneficial for all students to use facilities that are appropriately designed for any size, space, and use. Further investigation into public space design for individuals with extreme body stature could help to eradicate some of the obstacles and discrimination.

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Original Research Article

Functional Independence, Quality of Life and Participation of Stroke Survivors in the Rural Community- A Cross-Sectional Survey

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ABSTRACT

Background: In low- and middle-income countries (LMICs) like India, most stroke survivors reside in rural communities deprived of comprehensive rehabilitation, often resulting in long-term disabilities. The objective of our study was to identify the level of functional independence, quality of life and community integration of stroke survivors and to find the burden and quality of life of their primary caregivers.

Study design: A cross-sectional survey was conducted.

Study setting: The study was conducted in a rural community setting served by a tertiary care hospital in South India.

Method: A total of 30 stroke survivors and their primary caregivers were included. Demographic and stroke-related information was gathered from our database, and clinical characteristics were obtained using self-designed data form. Modified Barthel Index (MBI), Fugl-Meyer Assessment of Upper Extremity (FMA-UE), World Health Organization Quality of Life-BREF (WHOQOL-BREF), National Institute of Health Stroke Scale (NIHSS), Community Integration Questionnaire (CIQ) and Caregiver Burden Scale (CBS) were used as outcome measures.

Results: Participants showed a moderate level of impairment (mean ± SD 34±24) and independence (mean ± SD 67±28), with a low level of community reintegration (mean ± SD 4±6) and quality of life. Caregivers of stroke survivors showed a moderate to severe burden (41±19). The quality of life of caregivers was better than the quality of life of stroke survivors in all the Quality-of-Life domains ($p<0.01$). The caregiver burden moderately correlates with all their Quality-of-Life domains: psychological domain ($r = -0.507$; $p=0.004$), social relationship domain ($r = -0.506$; $p=0.004$), and environment domain ($r = -0.663$; $p<0.01$), but not in the physical health domain ($r = -0.218$; $p=0.247$).

Conclusion: Stroke survivors in rural South India showed moderate functional independence, while caregivers faced moderate to severe burden. The study highlights the need for accessible, community-based rehabilitation and support systems to improve the quality of life for both groups.

Keywords: functional independence; participation; quality of life; rehabilitation; stroke.

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INTRODUCTION

Stroke is the second leading cause of death and third leading cause of death and disability in the world (Feigin et al., 2022). Stroke results in impairment in physical, psychological and social functions, leading to dependence in Activities of Daily Living (ADL) and reduced social participation, which in turn influences the Quality of Life (QoL) of stroke survivors (Kim et al., 2014). The treatment of these deficits is mainly focused on the acute and sub-acute phases as most of the recovery occurs in the first few months after the stroke. However, the majority of the stroke survivors are still left with long-term disability, including physical limitations, psychosocial and cognitive problems, even after undergoing rehabilitation (Lincoln et al., 2000; Patel et al., 2006; Wade et al., 1992). Literature also stated that 50% of the stroke survivors went back to the community with impairments, requiring assistance from caregivers along with continuous community support in order to promote community reintegration (Chau et al., 2009; Mayo et al., 2000).

Many studies have been conducted to explore the level of participation and QoL of stroke survivors in the community. A study conducted among 6-months post stroke survivors in the community found that 33% of the participants showed reduced participation in Basic Activities of Daily Living (BADL), 51% in household tasks, 50% in travel, and 53% in meaningful activities, which led to social isolation and reduced activity levels (Mayo et al., 2002). It was found in a survey that 60% of the stroke survivors were dependent in their BADL, and their QoL was significantly lower (Hackett et al., 2000). Another study also found that stroke survivors had lower QoL and were functionally dependent in their ADL (Parikh et al., 2018). A study conducted among Swedish population also found that stroke survivors, two years post-onset, have declined in their independence level after discharge, and they were more dependent in BADL and Instrumental Activities of Daily Living (IADL) (Grimby et al., 1998). These studies revealed that many stroke survivors are left with disability without continuous support from the community, which reduces their participation and QoL.

Caregivers play an important role in the care and recovery of stroke survivors (Chaiyawat & Kulkantrakorn, 2012; Good et al., 2011), yet they are also impacted by the disabilities resulting from the stroke (Ganjiwale et al., 2016). Caregivers may experience a burden that leads to the deterioration of their health and QoL. The burden increases with the duration of caregiving (Gbiri et al., 2015). Caregivers undergo problems such as loss of independence, fatigue, inadequate time for self-care, and managing physical symptoms (Grant et al., 2004). Studies showed that the burden was more on female caregivers and on caregivers of severe stroke survivors (Menon et al., 2017). Therefore, the objective of our study was to identify the level of functional independence, QoL, and community participation among stroke survivors residing in rural South Indian community and to find the burden and QoL of primary caregivers of stroke survivors.

STUDY OBJECTIVES:

1. To identify the functional independence, QoL, and community participation of stroke survivors living in the rural South Indian community.
2. To compare the QoL of stroke survivors and their primary caregivers living in the rural South Indian community.
3. To correlate the burden and QoL of primary caregivers of stroke survivors living in the rural South Indian community.

METHODS

PARTICIPANTS:

The study included 30 stroke survivors and their primary caregivers living in a rural South Indian community. The details of stroke survivors were identified from the database of the department of Community Health of a tertiary care hospital. The inclusion criteria for participants were persons with a diagnosis of first-ever ischemic or haemorrhagic stroke within 2 years from the date of onset, those who were able to communicate verbally or non-verbally, and who were willing to participate in the study. Persons who had difficulty in comprehending and responding to the questionnaires were excluded from the study. The criteria for caregivers were caregivers who are significant family members and provided support with the basic needs of stroke survivors and were willing to give informed consent to participate in the study.

STUDY SETTING:

The study was conducted in a rural community block of a tertiary care hospital in South India. The block consists of 88 villages with a total population of approximately one lakh twenty thousand people.

STUDY DESIGN:

A cross-sectional survey was done to obtain the data from the participants. The data collection was done for 4 months, from December 2017 to March 2018. The outcome measures were administered by trained occupational therapists, and the approximate duration taken to administer the measures was 45 minutes.

OUTCOME MEASURES:

Demographic and stroke-related information was gathered from the database and from the stroke survivors and their caregivers using a self-designed data form. The functional independence was assessed using the Modified Barthel Index (MBI). The MBI is a measure of activities of daily living, which shows the degree of independence of a person from any assistance. It covers 10 domains of functioning: bowel control, bladder control, as well as help with grooming, toilet use, feeding, transfers, walking, dressing, climbing stairs, and bathing. It is a 10-item scale where each activity is given one of the five levels of dependency ranging from 0 (unable to perform task) to a maximum of 5, 10, or 15 (fully independent). Each activity is given a score ranging from 0 (unable to perform task) to a maximum of 5, 10, or 15 (fully independent- exact score depends on the activity being evaluated). A total score is obtained by summing points for each of the items. Total scores may range from 0 to 100, with higher scores indicating greater independence. This scale was found to have good internal consistency, the Cronbach's alpha = 0.89, and good concurrent validity (Hsueh et al., 2001; Ohura et al., 2011).

The motor assessment was done using the Fugl-Meyer assessment of Upper Extremity (FMA-UE). The FMA-UE is a stroke-specific, performance-based impairment index. It is designed to assess motor functioning, balance, sensation, and joint functioning in patients with post-stroke hemiplegia. The interrater reliability of the scale is found to be 0.97, and the construct validity of the tool was found to be r=0.86-0.89 (Sanford et al., 1993).

QoL of stroke survivors and caregivers was assessed using the World Health Organization Quality of Life- BREF (WHOQOL-BREF). The WHOQOL-BREF contains a total of 26 questions. To provide a broad assessment, one item from each of the 24 facets contained in the WHOQOL-100 has been included. In addition, two items from the overall quality of life and general health facet have been included. Overall, it consists of four domains, including physical domain, psychological domain, social domain, and environmental domain. The WHOQOL-BREF presented good reliability (Cronbach's alpha 0.9207), converging validity (0.382 < r < 0.753; p < 0.001), discriminant validity, and criterion validity (0.554 < r < 0.778; p < 0.001) (Ohaeri & Awadalla, 2009).

Community reintegration was assessed using the Community Integration Questionnaire (CIQ). The CIQ consists of a total of 15 questions. The overall score, which represents a summation of the scores from individual questions, can range from 0 to 29. A higher score indicates greater integration, and a lower score reflects less integration. The scale also had excellent test-retest reliability (ICC= 0.9970) (Singh & Sharma, 2015).

The caregivers' burden was assessed using the Caregiver Burden Scale (CBS). CBS consists of a total of 21 questions. It is used to assess perceived burden among people caring for others with disabilities. For each item, caregivers indicate how often they felt that way, and responses are rated from 0 to 4 (0 = never, 1 = rarely, 2 = sometimes, 3 = quite frequently, and 4 = nearly always). The internal consistency of the CBS was high (Cronbach's α 0.875). The item total correlations ranged from 0.138 to 0.708 and were all statistically significant (P < 0.01) (Lu et al., 2009).

Stroke severity was assessed by using the National Institute of Health Stroke Scale (NIHSS). NIHSS is a tool used to quantify the impairment caused by a stroke. The NIHSS is composed of 11 items, each of which scores a specific ability between 0 and 4. For each item, a score of 0 typically indicates normal function in that specific ability, while a higher score is indicative of some level of impairment. The individual scores from each item are summed to calculate a patient's total NIHSS score. The maximum possible score is 42, with the minimum score being 0. The NIHSS has moderate-to-high reliability (intra-rater =0.66 to 0.77; inter-rater= 0.69) and moderate concurrent validity (r = 0.61 and 0.68) (Kasner et al., 1999).

SAMPLE SIZE:

The sample size was calculated based on mean ± SD of NIHSS score reported (Raju et al., 2010) as 2.1 ±2.1. Assuming a 25% shift on both sides, a precision of 0.525 was considered. So, to detect a mean level of 2.1 with a precision of 0.525 and SD of 2.1, with 95 % CI, a sample size of 64 was estimated.

DATA ANALYSIS:

The data was summarized as frequency and percentage for categorical variables such as age, gender, duration of stroke, and stroke severity. For continuous variables such as FMA-UE, MBI, and QoL, mean ± SD was used. The comparison of demographic variables with functional outcomes was done using the Wilcoxon rank sum test (Mann-Whitney test). The association of caregiver burden with QoL was done using Pearson Chi-square correlation. The comparison between QoL of stroke survivors and their caregivers was done using independent t-tests. A p-value of 0.05 was considered statistically significant.

STATEMENT OF ETHICS:

Ethical approval for the study was obtained from the Institutional Research and Ethics Committee (IRB min No. 10962 dated 07.11.2017) before the commencement of the study.

RESULTS

The study included 30 stroke survivors and their caregivers living in the community. Initially, 38 potential stroke survivors were identified from the database. Among those, 2 persons could not be located, and 6 persons had deceased (16%), resulting in a final sample of 30 participants. The demographic and clinical characteristics of stroke survivors are shown in Table **1**. The demographic characteristics of caregivers are shown in Table 2.

Table 1: Demographic and clinical characteristics of stroke survivors

VARIABLES		n (%)
Age	<=60	14 (47)
	>60	16 (53)
Gender	Male	12 (40)
	Female	18 (60)
Duration of stroke	<1 year	20 (67)
	>1 year	10 (33)
NIHSS	1-mild	12 (40)
	2-moderate	16 (53)
	3-severe	2 (7)

Table 2: Demographic characteristics of caregivers

VARIABLES		n (%)
Age	<=60	26 (87)
	>60	4 (13)
Gender	Male	7 (23)
	Female	23 (77)
Hours of assistance	<3 hrs.	8 (27)
	3-6 hrs.	4 (13)
	>6 hrs.	18 (60)
Relation	Spouse	13 (43)
	Son/daughter	10 (33)
	Relative	7 (23)

Table **3** shows the level of impairment, functional independence, and community integration of stroke survivors living in the community.

The mean FMA, MBI & CIQ scores were 34±24; 67±28; 4±6, respectively. According to FMA and MBI, higher score indicates less impairment and better functional status respectively. The results indicated that the participants showed moderate levels of impairment and functional status. Out of 30 participants, the majority (87%) were not reintegrated into the community and have scored 0 (n=13) and less than 10 (n=13) in the CIQ. The mean duration of post stroke was 8 ± 6 months.

Table 3: Level of impairment status, functional independence, and community integration of stroke survivors

VARIABLES	Mean (SD)
FMA-UE	34 ± 24

Modified Barthel Index	67 ± 28
Community Integration Questionnaire	4 ± 6

Table **4** shows the comparison of QoL of stroke survivors and their caregivers.

There is a significant difference found in all four domains of WHOQOL-BREF between stroke survivors and their caregivers- Psychological domain (p<0.01), physical health domain (p<0.01), social relationship domain (p<0.01), and environment domain (p= 0.003).

Table 4: Comparison of Quality of Life of stroke survivors and their caregivers

VARIABLE	Stroke survivors n = 30	Caregivers n = 30	p-value
	Mean (SD)	Mean (SD)	
WHOQOL-BREF			
Physical domain	43 ±11	56 ±10	<0.01
Psychological domain	36 ±12	57 ±10	<0.01
Social domain	42 ±14	55 ±14	<0.01
Environmental domain	45 ±15	56 ±13	0.003

*p value was set at 0.05

Table **5** shows the correlation between caregivers' QoL and their burden.

A significant negative correlation was found between caregiver burden and psychological (r = -0. 507; p=0.004), social relationship (r = -0. 506; p=0.004), and environment domains (r = -0. 663; p<0.01) of WHOQOL-BREF. There was no significant relationship found between physical health (r = -0. 218; p=0.247) and burden of the caregivers.

Table 5: Correlation between caregivers' Quality of Life and burden

VARIABLE	N	CBS	
		r	p-value
Physical health	30	-0.218	0.247
Psychological		-0.507	0.004*
Social relations		-0.506	0.004*
Environment		-0.663	<0.01*

*p value was set at 0.05

DISCUSSION

Stroke survivors residing in rural communities are deprived of comprehensive rehabilitation due to inaccessibility, lack of awareness, and financial resources. This may lead to increased physical and psychological impairments, reduced activity and participation levels, and reduced QoL and life satisfaction. In recent times, researchers and rehabilitation professionals have been focusing more on providing rehabilitation services in the community (Pitthayapong et al., 2017; Sureshkumar et al., 2015). However, rehabilitation strategies developed for one community may not be generalizable to other communities due to various factors such as education level, people's beliefs, government health policies, and lack of resources. Understanding the stroke survivors and their caregivers' needs and expectations, caregiver burden, stroke survivors' level of functioning, participation, and QoL will help in developing appropriate rehabilitation strategies for stroke survivors residing in our study setting.

On studying the level of impairment, functional independence and community reintegration, it was found that stroke survivors scored an average of 34 ± 24 on the FMA-UE, 67 ± 28 on the MBI and 4 ± 6 on the CIQ, which showed that they had moderate level of impairment, moderate independence in their ADL and a very low level of community reintegration (refer to Table 3). On comparing the severity of stroke of our study participants, our results showed a similar pattern with a study done in UK, which reported severity of their stroke participants as mild (33%), moderate (30%) and severe (19%) and death (18%) (Magalhães et al., 2014) at the end of 3 months post-stroke. Their participants were taken from both rural and urban areas, and they have used the Modified Rankin Scale to classify stroke survivors' severity. Our data suggested that the majority of our rural stroke survivors fall under the mild and moderate category, and the death rate was 15%. Though many of them had mild (40%) to moderate (53%) stroke based on NIHSS, they were found to have significant impairment, activity limitation, and participation at the end of 8 months post stroke. Stroke survivors who were more physically independent were able to reintegrate better into the community (Hamzat et al., 2014). One of the studies also reported low levels of community reintegration (11%) among stroke survivors in Hong Kong (Pang et al., 2007).

Many long-term studies on stroke survivors have shown an association between impairment, ADL, and participation. The ADL and participation in house chores and leisure activities have been found to improve stroke survivors' muscle strength and endurance (Mutai et al., 2016). Few prospective studies have examined changes in the ADL in home-dwelling stroke survivors and have reported only a slight increase in ADL scores over time (Hartman-Maeir et al., 2007; Kim et al., 1999; Whiting et al., 2011). All the studies mentioned above clearly demonstrated that community-dwelling stroke survivors have lesser engagement in their ADL and social participation, which in turn influence their impairment status. All the 30 stroke survivors who participated in our study did not undergo proper rehabilitation after the acute management from the base hospital and were discharged to the community very early after the onset of the stroke. Despite the absence of comprehensive rehabilitation, the majority of these stroke survivors were regularly followed up at their homes by our community healthcare team comprising doctors, nurses, occupational therapists, and community health aids, which likely contributed to their moderate level independence after stroke.

Stroke survivors in our study showed lower QoL scores in all four domains (physical 43 ± 11; psychological 36 ± 12; social 42 ± 14 and environmental 45 ± 15) (refer to Table 4) compared to previously published literature (physical 54 ± 15; psychological 58 ± 15; social 68 ± 20; environmental 68 ± 18) from an urban community in India (Raju et al., 2010). Poorer QoL was associated with greater levels of physical disability and reduced social interaction in a study done in Tanzania, which also reported that demographic variables appeared to be much less significant (Howitt et al., 2011). These findings are in concordance with our results.

On comparing the QoL of stroke survivors and their caregivers, the QoL of caregivers was found to be better in all four domains of WHOQOL-BREF (refer to Table 4). These findings were similar to previous studies where caregivers' QoL was better than the patients' QoL (Dayapoglu & Tan, 2010; Ganjiwale et al., 2016). The comparison between the QoL of stroke survivors and their caregivers provides important contextual insights into the distinct challenges faced by each group, which can inform targeted interventions. Stroke survivors often experience physical and functional limitations, such as reduced mobility, difficulty performing ADL, and dependency on caregivers. These factors directly impact their physical health domain of QoL and contribute to emotional distress due to loss of independence (Kim et al., 2014). Understanding stroke survivors' lower QoL highlights the need for accessible rehabilitation services that address functional independence and emotional well-being. Caregivers face a different set of challenges, primarily stemming from emotional and social burdens associated with caregiving responsibilities. While their physical health may not be as severely impacted as stroke survivors, caregivers often experience stress, fatigue, and social isolation, which affect their psychological and social domains of QoL (Gbiri et al., 2015; Grant et al., 2004). Comparing their QoL with stroke survivors helps contextualize how caregiving roles influence their overall well-being.

On studying the correlation between caregivers' burden with their QoL, a moderate correlation was found in all the domains except for the physical health domain (refer to Table 5). Most of the caregivers in our study were women (77%), who were spouses (43%), and who offered assistance for more than 6 hours a day (60%). Therefore, they would have experienced more burden due to the continuous care they had to give to the stroke survivors and due to their role shift, which would have caused additional responsibilities in the family. Our findings were similar to two studies conducted in India, which stated that women who were spouses and those who have provided longer hours of assistance had increased burden (Bhattacharjee et al., 2012; Menon et al., 2017).

CONCLUSIONS

Stroke survivors in rural South India demonstrated moderate levels of functional independence, highlighting the urgent need for accessible and effective rehabilitation services tailored to their unique challenges. The comparison between the QoL of stroke survivors and their caregivers provides important contextual insights into the distinct challenges faced by each group, which can inform targeted interventions. Caregivers, on the other hand, experienced moderate to severe burden, underscoring the necessity of implementing robust caregiver support systems. The observed correlations between caregiver burden and Quality-of-Life domains, except physical health, emphasize the multifaceted impact of caregiving on overall well-being. These findings call for decentralized, low-cost rehabilitation models and community-based interventions to improve the quality of life for both stroke survivors and their caregivers in resource-limited rural settings.

LIMITATIONS

One of the important limitations in our study was sample selection. We have restricted our inclusion criteria to stroke survivors within two years from the date of onset. Another limitation was that all the stroke survivors residing in the community were not included due to inaccessibility and time constraints. This survey could have extended to other stroke survivors in the entire community for the generalization of results.

Ethical approval: Ethical approval was sought and obtained before the commencement of this study. The participants gave their informed consent after the purpose and nature of the study were explained to them.

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Data Availability Statement: The data that support the findings of this study are available from the corresponding author upon reasonable request.

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Original Research Article

Stakeholders' perspectives on a pilot project focusing on improving access to primary healthcare for adults with disability in Santiago Atitlán, Guatemala

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ABSTRACT

Background: Primary health care (PHC) has been identified as a key strategy in not only achieving Universal Health Coverage but also in Goal 3, Health, of the United Nation's Sustainable Development Goals. However, an estimated 4.5 billion people, more than half of the global population, lack access to essential health services, including PHC. Research shows that despite having often an increased need for healthcare, people with disabilities experience greater barriers to access health care due to discrimination, stigma, and social disadvantages. People with disabilities make up 16% of the world's population. Community-Based Rehabilitation (CBR) is a strategy developed to meet the needs of people with disabilities in low- and middle-income countries. It is a multisectoral approach based on implementing services through collaboration among governmental and non-governmental sectors, people with disabilities and their families, and the broader community.

Aim: This paper aims to explore the perspectives of the various stakeholders on a pilot project developed to improve access to primary healthcare for people with disabilities as part of a local CBR program in Santiago Atitlán, Guatemala.

Method: A qualitative approach was used to explore the perspectives of the program's stakeholders. A total of 27 participants were interviewed.

Results: Four themes were identified: program challenges, facilitators, impact and sustainability. The results indicate that despite challenges faced by the program, there was a positive impact on the community and improved access to PHC for people with disabilities.

Conclusion: CBR programming has the potential to increase the inclusion of people with disabilities in mainstream health services.

Implications: There remains a need for ongoing research on the impact of CBR-supported programming in improving access to and use of mainstream health care services by people with disabilities.

Keywords: Low- and Middle-income countries, Central America, Disability, Community-Based Inclusive Development, Community-Based Rehabilitation

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INTRODUCTION

Primary health care, recognized as a comprehensive community approach to health, has been identified as a key strategy in not only achieving Universal Health Coverage (UHC) but also Goal 3, Health, of the United Nation's (UN) Sustainable Development Goal (SDG): 'ensuring healthy lives and promotion of wellbeing for all, at all ages' (WHO, 2018). It is estimated that 80-90% of people's healthcare needs across their lifetime can be met at the PHC level (Lancet, 2018; WHO, 2018). In 2021, however, an estimated 4.5 billion people - more than half of the global population - lacked access to essential health services, including primary healthcare (WHO, 2023a). Marginalized populations defined by age, gender, income, ethnicity, sexual orientation, and disability often experience significant barriers to healthcare services. Research shows that despite their increased need for healthcare, people with disabilities experience greater barriers to access due to discrimination, stigma, and social disadvantages, including physical and environmental barriers and other factors (Froehlich-Grobe et al., 2016; Reichard et al., 2017; Rotarou & Sakellariou, 2017). People with disabilities make up the largest minority group in the world, with an estimated 16% of the world population living with some form of disability (WHO, 2023b). This makes it impossible to meet a number of the SDGs, including Goal 3, Health, without considering the inclusion of people with disabilities (Kuper & Heydt, 2019; WHO, 2023b).

Community-Based Rehabilitation (CBR), also known as Community-Based Inclusive Development (CBID), was originally developed in the 1970s as a strategy to meet the needs of people with disabilities in low- and middle-income countries (LMICs) (Khasnabis et al., 2010). It is a multisectoral approach that delivers services through collaboration among governmental and non-governmental sectors, people with disabilities and their families, and the broader community (Khasnabis et al., 2010). Health is one of the five key sectoral components of CBR, consisting of promotion, prevention, medical care, rehabilitation and provision of assistive devices. In many locations where health is the focus, CBR programs work closely with the 'mainstream' health sector, providing services to the whole population to promote an "inclusive health" approach and ensure that the needs of people with disabilities and their family members are addressed alongside those of others (WHO, 2010). While in some cases this may include setting up alternative or parallel specialist rehabilitation services, many contemporary CBR programs focus on supporting and enhancing existing mainstream health provision to become more inclusive, specifically in the areas of PHC services, recognizing it's essential role in the areas of health promotion, prevention, and medical care (CBM, 2016a; Iemmi, Kuper & Blanchett et. al., 2016; WHO, 2010). PHC is recognized as a whole society approach to health, extending beyond primary care, which is the first level of care provision and a component of the primary healthcare approach, although the two terms are often used interchangeably (Global Report on Health Equity for Persons with Disabilities, 2022). While there are a number of studies and reports on CBR and its use across LMICs, limited research has focused on access to PHC, particularly in Latin America (Bachfischer et al., 2023; Besoain-Saldaña et al., 2020; Grech, 2015).

Despite having the largest economy in Central America, Guatemala, which is home to 17 million people, continues to face the highest rates of poverty and inequality in the region (The World Bank, 2020). Government healthcare spending in Guatemala is the lowest in Central America at 5.82% of GDP in 2022 (Guatemala, n.d.). What is more, it has the highest coverage gaps in basic healthcare with the lowest healthcare to inhabitant ratio in the region (International Monetary Fund, n.d.). The country is administratively divided into 22 departments, with a centralized healthcare system and a constitution that states that every citizen has the right to universal healthcare (The World Bank, 2020). The public healthcare sector, however, is highly underfunded, with funding gaps resulting in the lack of basic medicine and equipment (Samuel et al., 2020). These system inadequacies are even more marked in rural areas, which often have large indigenous populations (Pan American Health Organization, n.d.; Samuel et al., 2020). The International Monetary Fund recommends that the short-term goal for Guatemala should be to enhance its primary healthcare coverage (International Monetary Fund, n.d.).

According to a national disability survey conducted in Guatemala in 2016, it was estimated that Guatemala's all-age prevalence of disability was 10.2% with the greatest prevalence of limitation amongst adults being anxiety and depression (9.3%), followed by mobility (8%), vision (4.2%) and hearing impairments (4%), with 44% of adults with disabilities experiencing significant limitations in more than one functional domain (CBM, 2016a). The results also indicated that about 31% of all households have at least one person with a disability and that families including people with disabilities were more likely to be in the lower socio-economic status groups, have larger household sizes, and a higher dependency ratio with a lower proportion of household members who were working compared to households without a family member with a disability (CBM, 2016b). This places these families at greater risk of financial hardship and will affect how they seek and access healthcare services.

The aim of this paper is to explore the perspectives of the various stakeholders, including people with disabilities and service providers, on a pilot project aimed at improving access to health services, specifically primary healthcare for people with disabilities as part of a larger CBR program in Santiago Atitlán, Guatemala.

METHODS

Study Setting

Santiago Atitlán, located in the southwest region of Guatemala, in the Department of Sololá, is a municipality divided into 10 districts called "Cantones" (Kondo et al., 2014). Five of these are designated as urban, two as semi-urban and three as rural (Kondo et al., 2014). According to the census conducted by the municipality in 2017, Santiago Atitlán had a population of 49,631 (Consejo Municipal de Santiago Atitlán, Solola, 2020). The majority of the population is of indigenous Mayan descent, and Santiago Atitlán is recognized as the capital of the Tz'utujil people, with most speaking Tz'utujil and having strong traditional beliefs. PHC services, provided by the Ministry of Health (MOH) in the region, are delivered through a central health center called the Centro de Salud and respective smaller health posts, puesto de salud, located in the various cantones. They are staffed primarily by nurses at the central health center and auxiliary nurses in the health posts and in the community.

Santiago Atitlán is also home to an organization of people with disabilities (OPD) known as ADISA (Asociación de padres y amigos de personas con discapacidad de Santiago Atitlán). Although ADISA was legally established as a nonprofit and non-governmental organization in 2013, it started working with the community in 1998 with a mission to assist, defend and further the rights of people with disabilities using community-based inclusive development strategies informed by the WHO CBR guidelines (ADISA, n.d.). Their CBR program includes a range of projects targeting the different pillars of the CBR matrix, including health. Under the health pillar their services normally include access to assistive devices, rehabilitation, and access to medical care, supporting people with disabilities to access specialized services and diagnostics.

In 2018, ADISA started a 3-year pilot project under its CBR health program, in collaboration with the local division of the MOH, to improve access to healthcare, including primary healthcare for people with disabilities in Santiago Atitlán. The aim of the project was to establish an Inclusive Health Model involving inclusion and mainstreaming of care for people with disabilities at the individual, family and community level in collaboration with the local MOH, focusing on the right to health of persons with disabilities. As part of this program and parallel to the provision of rehabilitation services, ADISA's CBR team worked in close collaboration with the local MOH, including both staff and healthcare practitioners at the different levels and posts, and traditional healers in the community, to support people with disabilities to access healthcare. The program consisted of several components as listed below:

Increasing understanding of disability from the Mayan worldview of the Tz'utujil people of Santiago Atitlán through conversations with community leaders and midwives

Identification of people with disabilities and supporting them to access healthcare with an emphasis on children and adolescents through support of the healthcare team of each territory by ADISA's technical staff/CBR team

Monthly community meetings to increase awareness and education on disability

Bimonthly community visits to provide comprehensive care in remote areas

Advocacy and dissemination of results of the work carried out to the municipal authorities and other bodies as relevant.

Study design

A qualitative approach was used to explore the perspectives of the CBR program's stakeholders. This involved conducting in-depth interviews with both people with disabilities and key informants. Key informants consisted of CBR workers and administrative staff from ADISA, healthcare practitioners from the community, and staff from different levels of the local division of MOH.

Interviews were conducted in October 2019 by Goli Hashemi, the principal investigator, with the support of a Spanish interpreter and research assistant from Guatemala. The research assistant was trained in qualitative interview techniques, and the importance of confidentiality and direct translation to minimize changes or misinterpretation during the translation process. While most interviews were completed in Spanish, two were conducted in English with occasional support from the interpreter, and four were completed in Tz'utujil, using an additional interpreter and requiring double translation.

Interviews with people with disabilities took place either at their homes or at ADISA, and interviews with the healthcare stakeholders took place at their place of employment or their home. Each interview lasted between 60-80 minutes. With the permission of the participants, all interviews were audio-recorded. They were then transcribed, anonymized and uploaded to NVivo 12 for data management and analysis. Data were thematically analyzed according to Braun and Clarke's (2006) process.

Ethical approval was received from the Ethics Board at the London School of Hygiene and Tropical Medicine in the United Kingdom, and the Comité Institucional de Ética-INCAP (Instituto de Nutrición de Centro América y Panama) in Guatemala. An information and consent sheet in Spanish was provided and reviewed item by item with each of the participants prior to the beginning of interviews. All participants who were approached consented and signed the consent forms. No incentives were provided for participation in the study.

Study Sample

Participants were selected through purposive and snowball sampling with support from ADISA, based on the primary author's request to include people with disabilities with a range of ages and impairments and key informants from the community who held various roles related to the pilot project. A total of 27 participants (15 people with disabilities and 12 healthcare stakeholders) were interviewed. Participants with disabilities consisted of 8 men and 7 women, representing an age range between 21 to 99 years. Participants had a range of impairments (Table 1). None of the people with disabilities had access to any health insurance. Key informants consisted of 8 women, 6 staff from the MOH, 5 staff from ADISA, and 1 independent practitioner (Table 2). Their experience in their respective positions at the time of the interviews ranged from 1- 15 years, with eight of them providing direct clinical care.

Table 1: Characteristics of participants with disability

Characteristics	Total, N
Gender	
Male	8
Female	7
Age (years)	
18-30	2
31-40	2
41-50	5
51-60	2
>60	4
Type of impairment	
Mobility	2
Visual	1
Hearing	1
Mobility and Sensory	6
Psychiatric/mental illness	3
cognitive	2

Table 2: Characteristics of key informants

Characteristics	Total, N
Gender	
Male	4
Female	8
Position	
Administrative	4
Physical therapy	2
Nurse	2
Auxiliary Nurse	2
Health assistant	1
midwife	1
Years in position	
0-10	9
11-20	0
>20	3

RESULTS

At the start of the pilot project, to support the initiative, ADISA provided six intensive training sessions to community healthcare workers and nursing staff from the MOH on disability, to which community leaders and midwives were also invited. The topics ranged from causes of disability and prevention, identification of disability, differences between acquired and congenital disability and human rights of people with disability. In addition, ADISA staffed this program with three physical therapy technicians, a minimum of two interns and two volunteers at any given time to work closely with the community health workers from the local division of MOH to assist with community outreach and home visits.

Four primary themes were identified from the interviews: program challenges, program facilitators, program impact, and sustainability of the program.

1 Program challenges

Two of the program challenges identified were cultural beliefs and language barriers.

Cultural beliefs

Both people with disabilities and key informants stated that, according to the Mayan culture in the region, disability is perceived as a punishment from God or a higher power presenting itself as a form of possession by a spiritual being that would either resolve on its own or with appropriate treatment from a traditional healer. As a result of such beliefs, people with disabilities would often be hidden by their family members or may avoid coming out and interact with the community due to fear of stigma. Similarly, this belief would at times leads healthcare providers to avoid treatment of a person with a disability. The following quote demonstrates that perception:

> *"… the second thing, the cultural situation again…Sometimes they (the health professionals) feel that they (people with disabilities) are under a spell or something, that they (the patients) have received some kind of witchcraft over their bodies, so they prefer not to treat this kind of people." Male CBR worker*

Many members of the Tz'utujil community lacked trust in governmental institutions particularly MOH and healthcare professionals. This distrust was particularly strong as it is related to disability, resulting from fear that people with disabilities might be taken away and subjected to harm. Given this lack of trust, people with disabilities and their family members tend to only consider sources of support that they trust, such as traditional healers and community midwives, who incorporated familiar cultural practices, including traditional prayers, into their care.

> *"…the staff from the Centro de Salud have tried to reach the homes but they are rejected -they (families) are not allowing access into the house. It is not necessarily a person with a mental disorder or a disability – it may happen sometimes with any other family without any condition. Sometimes, general families reject the attention from Centro de Salud. For example there are children that do not receive their vaccinations. They trust more in the midwives and the historic culture." Female MOH staff*

As a result of the above, many people with disabilities would often not receive any medical attention for their disability-related or general healthcare needs, including preventive medicine/services.

Language Barrier

Language differences also posed a significant challenge. Some CBR workers, specifically physical therapy technicians who were not from the local area, had to rely on the nurses for interpretation as they did not speak Tz'utujil. The need to interpret for the CBR workers impacted the efficiency of the nurses' home visits, as they were required to meet daily visit quotas. Thus, doing visits with the CBR workers appeared to be a burden as shared by one of the CBR workers:

> *"………The other situation that I was telling you about is the situation of the nurses, that they have to fulfill their daily agenda and sometimes they are in a rush because they need to complete in a certain time. When I ask for a translation that takes more than 10, 15 minutes*

> *over their time, they get upset. They don't want to continue translating for me because they have to continue with their own job. So that has been the biggest limitation that I have faced…" Male CBR worker*

2 Program facilitators

Program facilitators included the extensive disability trainings provided by ADISA (described above) and the partnership between the CBR workers and the community nurses.

Training

All participant groups, including the CBR workers themselves, saw the benefits of the training provided by ADISA and wished for more. For some, specifically the midwives, this was the first time they had received training on disability. Unlike the short training they received while in school, the nurses felt that the training provided by ADISA prepared them for interactions and treatment of people with disabilities, taking into account their impairments and abilities. The nurses also expressed a desire for more training. This is reflected in the following quote:

> *"I would like to learn more about people with cerebral paralysis- sometimes I have to be honest- I don't know what to do with them… I had an experience when I visited a person and I remember the caregiver said that since you are a nurse feed that person. ….I was scared. I did not know what to do…" Female Nurse*

Partnership between CBR workers and community nurses

The partnership between the CBR workers and the community nurses resulted in improved acceptance of the nurses during household visits. This enabled the nurses to not only meet some of their community visit quotas but also provided them with the opportunity to educate and advocate for people with disability to their family members on the benefits of using healthcare services and going to health centers.

3 Program impact

Despite the challenges discussed, participants reported that there has been a positive impact on access to and quality of primary healthcare at the health centers because of the pilot program, specifically in relation to the program facilitators, namely the training and partnership between ADISA and the community nurses. One such impact is that people with disabilities and their families had started to have more trust in the health centers and were more receptive to the use of primary healthcare services. In fact, several key informants reported more people with disabilities were going directly to the health centers rather than going to ADISA for all their healthcare needs as demonstrated by the following example:

> *"the lady I told you about, the one with diabetes and that at the beginning didn't accept….with continued talking to her she changed her mind. She is no longer taking only natural medicine, she is already taking the prescriptions that we provide over here, and she is coming by herself to the regular consultation..." Female auxiliary nurse*

Key informants also reported that there has been an increased sense of empowerment among nurses and midwives to take a more holistic approach to patient care and to identify people with disabilities, resulting in greater numbers of referrals to ADISA for disability specific concerns.

While the perceptions of people with disabilities about health services remained mixed due to limited use of the primary healthcare services, those who had used primary healthcare services during that time frame reported notable improvements. The majority reported an improvement in access and quality of care at health centers and health posts. According to them, people with disabilities were no longer being turned away and were receiving the same attention as people without disabilities.

4 Sustainability of the program

When asked about the sustainability of the program, participants expressed mixed views. While a few were very optimistic, given ADISA's reputation within the community and success with programming, others, specifically CBR workers and the staff from the MOH, recognized that the sustainability and continuity of the program was very much dependent on government priorities and future funding. Despite the partnership with ADISA, some MOH community nurses expressed concerns about the fact that disability remains a low priority within the MOH, expressing that this was demonstrated by the MOH's budget, and the lack of data management/entry related to disability by the MOH, implying limited monitoring of the program by MOH. They also expressed concern with corruption and lack of funds when it came to the government and MOH, particularly with upcoming elections.

> *"We cannot say because currently it will depend on the government. They are working on a model that allows to work with other organizations but in January we will change our government and the new government will always bring new ideas and new models. Ideally, they would stay with this model we have now because the strengthening we have received from them, ADISA, is very good." Female Nurse*

DISCUSSION

The results of the study identified four primary themes from interviews with both people with disabilities and key informants involved in the pilot project implemented by ADISA and the MOH in Santiago Atitlan: program challenges, program facilitators, program impact, and sustainability of the program. These themes suggest that, despite the research being conducted midway through the duration of the pilot project, there appeared to be a positive impact on both access and quality of primary healthcare provided to people with disabilities. This was demonstrated by reported increases in the utilization of local health centers by people with disabilities for their primary healthcare needs and increased referrals to ADISA for disability services through increased identifications of people with disabilities. However, there were also ongoing challenges that impacted the program's efficacy.

One of the primary challenges was the influence of cultural beliefs. This is consistent with findings from past research indicating that cultural beliefs and attitudes act as a barrier to both accessing and receiving quality healthcare services amongst people with disabilities (Grech, 2016; Hashemi et al., 2020). Cultural beliefs, lack of trust and secrecy not only limit people with disabilities and their families in accessing public healthcare services but also hinder the identification of people with disabilities, resulting in large numbers of unidentified people with disabilities with untreated health conditions in the community. The findings indicate that people with disabilities accessed services either through traditional healers or went to ADISA with whom they had developed trust, for all their disability related concerns including healthcare needs. While research shows that including people with disabilities in the healthcare intervention planning is often missing (George et al., 2015; Grech, 2016), CBR can play a significant role in empowering people with disabilities and their family members by addressing cultural beliefs and fostering trust.

Through the CBR approach, ADISA was able to help people with disabilities and their families gain trust and feel comfortable with the public healthcare services, encouraging them to go directly to the health centers for their healthcare needs. This is important as healthcare decision-making starts within the home when an illness is identified and depends on several factors that make this decision-making both complex and unique for everyone, ranging from severity of illness to socioeconomic factors (Grech, 2016; Hashemi et al., 2023). CBR programming can not only help with some of the factors that influence decision-making, including awareness of rights of persons with a disability, but can also empower people with disabilities by providing them with choices they may have not have previously considered and increase their engagement through empowerment strategies (Biggeri et al., 2014; Magnusson et al., 2017).

Another challenge identified was the contrasting reputations of ADISA and the MOH. This not only impacted how services were perceived of and sought by people with disabilities but also how participants felt about the sustainability of the program. Some participants, particularly the key informants, seemed to have more faith in the sustainability of the program if it was managed by ADISA due to its good reputation in the community, success of past programming to date, political instability and the absence of monitoring and evaluation by the MOH for the disability inclusive program.

Given that regular monitoring and evaluation are integral to the success of CBR programs, ADISA could work more closely with the MOH and other healthcare providers to not only monitor the number of visits to and referrals of people with disabilities but also share their progress reports with the various stakeholders, including members of the disability community. This would increase transparency, potentially increase commitment to the program and demonstrate their continuous adjustments to the evolving needs of individuals with disabilities and the broader community as they focus on mainstreaming healthcare services.

Another key finding of the study highlighted the value of disability-specific education and training provided to the healthcare providers. It appears that the primary positive outcomes of the study were a direct result of the training provided by ADISA on disability. This finding aligns with the benefits associated with healthcare provider training on disability as part of in-service updates, enabling them to apply their learning in real time (Rotenberg et al., 2021). Providing comprehensive training to local community members, including healthcare workers, volunteers, and families is a cornerstone of CBR (Khasnabis et al., 2010). This capacity-building approach ensures that communities possess the required knowledge and skills to address the specific healthcare needs of individuals with disabilities not only at the healthcare service delivery level but also at the household level where initial healthcare decisions are made by people with disabilities and their families.

Finally, it is important to note that this paper focused only on access to PHC as part of the health component of the CBR strategies used by ADISA and not on the overall CBR programming and success. Given that CBR adopts a holistic approach that extends beyond addressing health needs to encompass social, economic, and environmental factors, this may have impacted the results of the study. By considering the broader context of individuals' lives, CBR programs contribute to the creation of a supportive environment that enhances overall well-being. This holistic framework further emphasizes the need for a multisectoral approach to CBR. Through working with the various sectors, CBR can increase the inclusion of people with disabilities in not only healthcare but also other aspects of community life.

Limitations

One key limitation of the study is related to potential losses in the double translation (for 4 interviews), which involved translating from Tz’utujil to Spanish and then to English, where there may have been discrepancies in translation due to limited training of

Tz'utijil interpreters. At times, extended conversation were observed between the study participant and the Tz'utujil interpreter, which was explained to be due to the lack of certain expressions related to disability in the Tz'utujil language. This necessitated the use of alternative expressions in describing certain concepts related to disability.

Lastly, while not exactly a limitation, it is worth noting that this study took place before the COVID-19 pandemic. It is anticipated that the pandemic must have had a major influence on the pilot project and its potential outcomes over the 2nd half of the pilot project, given the impact it had on the Guatemalan healthcare sector, exacerbating an already strained system (WHO, n.d.).

CONCLUSIONS

Access to primary healthcare for individuals with disabilities remains a critical concern, with various barriers impeding their ability to obtain essential health services. This paper contends that programming through community-based rehabilitation (CBR) programs or approaches offer a promising avenue for overcoming these challenges and fostering inclusivity within the mainstream healthcare systems. The study supports that while more work need to done to address cultural beliefs and attitude, a CBR approach can have a positive impact in facilitating improved access to mainstream primary healthcare for people with disabilities.

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Original Research Article

The Role of Communication and Information Access for Persons with Disabilities during the COVID-19 Pandemic in Thailand: A Qualitative Research

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ABSTRACT

Purpose: This study aims to explore the role of communication and information access for Thai persons with disabilities during the COVID-19 pandemic.

Method: The study employed a qualitative research approach, with an in-depth interview, as well as on-site and online focus groups. Criterion and snowball sampling were used to select participants. A total of 71 participants were recruited from different regions of Thailand.

Results: This research identified the role of communication in helping persons with disabilities and their caregivers during crisis time, separated into different levels of communication. First, the self-reflection, the particular context influenced persons with disabilities to play different active and passive roles in surviving the COVID-19 crisis. Second, group communication was beneficial in various aspects, such as gaining social capital and strengthening family cohesion, and these contradict some recent studies that reported sibling conflict during the lockdown. Finally, there was unequal access reflected from the mass communication level, and there was no critical, timely information, and insufficient accessibility support for PWDs in mainstream media.

Conclusion: Overall, this research advocates for a multi-level communication policy that ensures the inclusion of PWDs in crisis management. Recommendations include strengthening the role of Disabled People's Organizations, enhancing digital accessibility, and incorporating family-based communication support in social policies.

Keywords: crisis communication, information accessibility, COVID-19, qualitative research, persons with disability, SDG 3: Good Health and Well-being.

INTRODUCTION

An estimated 2.2 million individuals with disabilities hold official identification cards, accounting for approximately 3.08% of the Thailand's total population (Department of Empowerment of Persons with Disabilities, 2023). Persons with Disabilities (PWDs) need targeted support, especially during periods of crisis. Often burdened by comorbid health conditions and socioeconomic disadvantages, they have been disproportionately affected by the COVID-19 pandemic (Tan et al., 2023).

In Thailand, a significant number of persons with disabilities depend greatly on government services and community assistance to fulfill their daily needs. During the pandemic, numerous reports indicated severe disruptions in healthcare, education, and social support systems for Thai PWDs. For instance, Chaiteerakij et al. (2025) found that Thai children with “invisible” disabilities, such as autism or learning disabilities, faced critical challenges in accessing essential health and educational services. Similarly, nationwide surveys revealed that lockdowns intensified financial hardship and limited accessibility for families with PWDs.

These findings align with global studies. Authorities and researchers emphasize that while PWDs often demonstrate high awareness of COVID-19 and a strong willingness to follow public health guidance, they simultaneously face unique barriers in accessing timely and accurate information (Lakkhina et al., 2021; Phromphak et al., 2022). Mitigation strategies in several countries have demonstrated that, without disability-inclusive planning, the pandemic can undo decades of advancement in health and social equity (Tan et al., 2023). For example, in their global review, Tan et al. (2023) concluded that COVID-19 had an “inequitable and disproportionate impact on vulnerable populations,” including PWDs. In Thailand, although emergency measures such as financial aid, priority vaccinations, and designated shopping hours were implemented, many PWDs continued to face systemic barriers due to limited resources and inconsistent policy enforcement.

Communication is crucial in ensuring that persons with disabilities can access important information and services. It is the process of exchanging messages at intrapersonal, interpersonal, group, and mass levels, and is key to making informed decisions. While the Convention on the Rights of Persons with Disabilities (CRPD) upholds the right of PWDs to access information through all forms of media, and Thailand’s Persons with Disabilities Empowerment Act promotes communication accessibility , mainstream communication channels often fail to accommodate the needs of PWDs.

Globally, studies have reported that official COVID-19 information was frequently inaccessible to PWDs. These shortcomings included a lack of sign language interpretation, captions, and plain-language guides (Meltzer et al., 2025). An Australian survey of organizations producing accessible COVID-19 materials found chronic under-resourcing. These providers struggled with frequently changing health guidance, unclear source materials, and inadequate funding—factors that left many PWDs “without sufficient accessible information” (Meltzer et al., 2025). In the United States, similar issues arose: many state vaccine websites featured design barriers that made it difficult or impossible for PWDs to access updates or register for vaccinations (Guo et al., 2021).

Dobransky and Hargittai (2021) reported social media use in the United States during the early stages of the widespread pandemic. Their findings discovered that PWDs were more actively engaged with COVID-19-related information on social media compared to non-disabled users. PWDs participated at higher rates in sharing, interacting, and offering support. The study links this behavior to the previous experience of persons with disabilities using accessible digital tools, including features based on universal design, which allowed them to quickly and efficiently utilize these platforms for sharing information. The results highlight the critical role of inclusive online media in ensuring access to health information during times of crisis.

During the pandemic, digital technology proved to be a double-edged sword. While information and communication technology (ICT) enabled ongoing work, education, and social interaction amid physical distancing measures (Arjadi et al., 2022; Xie et al., 2023), it also highlighted existing inequalities. For persons with disabilities, digital media tools—such as social networks, messaging apps, telehealth services, and online learning platforms—served as valuable supports. However, in Thailand, access to these technologies has remained limited. A recent national survey found that only 27% of visually impaired individuals in Thailand were Internet users (Phochai et al., 2023). Several factors have been linked to reduced digital engagement among persons with disabilities, including advanced age, limited income and education, and higher levels of impairment. Studies from Europe and Asia have shown that individuals with disabilities are less likely to have reliable access to high-speed internet, own various digital devices, or use multiple technologies. Despite often exhibiting digital skills on par with the general population, their unique technological requirements frequently remain unmet (Duplaga, 2023; Johansson et al., 2021).

Where accessible technologies were available, they significantly helped reduce social isolation. Videoconferencing and social media played a key role in maintaining services and mitigating loneliness during lockdowns (Gabbiadini et al., 2020; Xie et al., 2023). A study in the United States by Xie et al. (2023) revealed that in 2020, adults with functional disabilities were more likely to use telehealth services compared to those without disabilities, with usage rates rising according to the severity of the disability. Nonetheless, the accessibility of online services varied widely. Jesus et al. (2021) reported that numerous tele-education and tele-rehabilitation platforms were ill-prepared to accommodate the needs of PWDs. Identified barriers ranged from non-intuitive user interfaces and lack of captions to the unaffordability of broadband services. Consequently, PWDs living in rural or economically disadvantaged Thai communities often found that digital solutions could not fully substitute for the lost in-person support (Jesus et al., 2021).

Therefore, addressing the academic gap in communication and information access for persons with disabilities (PWDs) is essential. Further knowledge development is needed to respond effectively to the complexities revealed during the COVID-19 pandemic. This study examines the role of communication in supporting PWDs in Thailand between 2021 and 2022. It focuses on three levels of communication: intrapersonal (internal reflection shaped by personal experience and context), group (collaborative processes in teams and small groups), and mass communication (broad dissemination of information). The study also explores how technology facilitated or hindered access to critical information and services for PWDs during the crisis.

METHODS

A qualitative research with in-depth interviews, as well as on-site and online focus groups, was conducted. Criterion and snowball sampling were used to select participants. A total of 71 participants were recruited from different regions of Thailand.

Participants

A total of 71 participants were recruited from the North, Northeast, South, and Central regions of Thailand, with 16,29,17, and 9 participants respectively. The participants were divided into two groups based on the following inclusion criteria:

a) 27 people with disabilities and 18 main caregivers (in case of severe disabilities and inability to communicate with PWDs).

b) 26 stakeholders from related service sectors for PWDs were also included, with the following individuals:
    - 8 participants from the health sector, including 4 physical therapists, 2 nurses, 1 health academic, and a doctor in a Sub-district Administrative Organization.
    - 16 participants from the education sector, including 4 school directors and 12 teachers.
    - 2 participants from livelihood and social engagement: 2 SAO officers (Sub-district Administrative Organization)

Furthermore, those participants were required to be 18 years old or above, able to communicate and provide information and willing to participant voluntarily in the research.

Instrument

A six-question guideline was developed. Those six open-ended questions were used to obtain data through in-depth interviews or focus groups to ensure the flexibility and readiness of participants and fieldwork.

Procedure

Research ethics approval was obtained from the Committee for Research Ethics (Social Sciences) Mahidol University: MUSSIR2021/158(B2). Participants' consent was obtained in advance, and official letters were issued before collecting data. In practice, data collection occurred between December 2021 and March 2022 under the COVID-19 safety measures. For instance, the appropriate research field was selected, and participants' risk information, symptoms of illness, and ATK (Antigen test kit) results were checked. The data collected involved conducting seven in-depth interviews and ten focus groups within various communities and fieldwork.

Data were collected in five regions of Thailand. The northern region included Chiangmai and Mae Hong Sorn provinces; The northeastern region included Udon Thani, Nong Kai, and Bueng Kan provinces; The southern region included Nakorn Si Thammarat and Krabi province, and the central region included Bangkok and Chonburi province.

Data Analysis

The raw data from the tape recording from focus groups and In-depth interviews were transferred to a full transcript for triangulation. The researchers subsequently identified and grouped the responses into the related main themes and sub-themes, encoding the data accordingly. Participants' transcripts were manually analyzed to extract the main findings. The data were decoded, conclusions were drawn and critiqued into the related main themes and sub-themes.

RESULTS

Table 1: shows participants' characteristics

	Type of disability	Type of stakeholders	Totals	Code
Person with disability	1. Physical Disability = 8 2. Visual Impairment = 14 3. Learning Disability = 2 4. Hearing Impairment = 1 5. Autism = 1 6. Intellectual Disability = 1	-	27	P 1-27
Caregivers	-	1. Caregivers for persons with Intellectual Disability = 5 2. Caregivers for persons with Autism = 7 3. Caregivers for persons with Learning Disability = 2 4. Caregivers for persons with Physical Disability = 3 5. Caregivers for persons with Visual Impairment = 1	18	CG 1 - 18
Health sector	-	1. Physical Therapists = 4 2. Nurses = 2 3. Public Health Professionals = 1	8	H1-8

	4. Village Health Volunteers = 1		
Education sector	1. school directors = 4 2. teachers =12	16	E 1-16
Livelihood and social engagement	SAO officers (Sub-district Administrative Organization) = 2	2	L1-2
Total		71	

The findings from the open-ended questions revealed that participants narrated their experiences with obstacles related to the role of communication and information access during the crisis. The results are portrayed according to the following levels of communication.

Intrapersonal communication: "Living with a disability already entails significant challenges."

The data collected from in-depth interviews conducted in both rural and urban areas revealed different perspectives on the hardship faced during the pandemic. PWDs living in remote areas primarily relied on word-of-mouth information from family members, neighbors, or the mainstream program, yet community broadcasting social media are not the main channels for them. Those in urban contexts utilized alternative media platforms such as social media and messaging applications more effectively than mainstream media.

> "*...I have no smartphone; it is not necessary for my daily life. For COVID information, I perceived from my daughter and my wife, in case of community service, they announced via community broadcasting...*" *(P7, PWDs.)*

In exploring the reflection of self-consciousness during the pandemic, researchers highlighted critical issues experienced by other individuals, including job losses, confinement at home, limited access to medical services, and students facing school closure. These circumstances resulted in unexpected behavior and an increased suicide rate due to heightened anxiety and depression. Surprisingly, participants narrated that they did not experience additional suffering or feel any worse during the pandemic compared to their normal situation. They explained that living with a disability had already presented them with numerous obstacles throughout their lives.

> *"… I heard tourists rarely visit shops and restaurants, along with a decrease in tourism. Have you been affected by economic hardship? It may bring about financial challenges. Your children stopped working. How do you feel about this situation."? (Researcher1)*

> "*...I did not feel down from the COVID-19 situation, although economic hardship affected my family, we could handle it and did not suffer from this much. I have needed permanent work since before the widespread. I used to apply for a job, but they did not accept me because of my physical impairment. I am a housewife and look after my grandchildren...*" *(P5, PWDs.)*

The self-reflection (intrapersonal communication) of participants was revealed through dialogue as the researcher addressed the hardship brought about by COVID-19. Interestingly, participants did not express thoughts of self-harm. Instead, there was a sense of empowerment observed among participants who held leadership positions within disability organizations. They reflected on the significance of combating discrimination and stigma in their lives. Thus, during this challenging period of the crisis, individuals did not solely focus on their own hardships; rather, they expressed concern for the well-being of others.

Group Communication: Social Capital, Family Cohesion, and Digital Networks

Benefit for financial support

Based on the data collected, it was found that there was a strong connection between members of the PWDs community and their associated disability region during hardship situations. For instance, associations for the blind were connected with local savings groups, local enterprise networks, or local organizations for PWDs in various areas of Thailand. These local collaborations were crucial in providing financial support to PWDs and their families.

Leader of such associations played a pivotal role in facilitating group communication and contributed to finding solutions to the economic system problem. Top-down communication was used to inform and connect with the higher-level organization to seek support for alternative occupations, finance, and charitable life support.

> *"...For the blind organization, we connected to the country and regional blind organizations to support us. We needed them to provide more channels to show us how to work online or run the agriculture project. We were stuck at home due to social distancing measures, and blind people could not go out to sell the lottery as usual. We (the Local Association of the Blind) consulted with the committee to cope with this problem." (P1, PWDs.)*

> *"…Before COVID, we had established funding for our blind members to collect money separate from wages. We aim to help a member who needs financial support obtain a required loan, and we have no interest charges. Moreover, we set up a group of enterprises to encourage the blind members to work independently…" (P20, PWDs.)*

An empowered family communication

Family communication was identified as a part of group interaction, serving as a vital emotional and practical support system for PWDs. During COVID-19, effective communication within the family shows mutual understanding and facilitates joint problem-solving. Insights from in-depth interviews and focus group discussions highlighted the importance of these intimate dialogues in helping individuals cope with the crisis.

P4 (PWDs), one of the participants with physical disability shared that he has two children who are preparing to attend university next year. However, they experienced financial hardship during the pandemic. In response, he decided to have a direct conversation and openly shared the family's financial situation with his children. After a family conversation, he realized that his children were no longer the young kids he once thought they were, and they tried to seek a way out of this situation.

> *"…they are always a kid in my eyes, but in this situation, I was pleasantly surprised by their understanding and perspective on our situation. They grasped the importance of saving money and stepped out of this bad situation together… I'm also proud of their sibling relation….''*

Another illustration is by C7(Caregiver), the father of a student with mental disability. He recounted a meaningful story about his daughter that led to a transformative experience for him. He admitted that he had never trusted in his daughter's ability until the COVID-19 situation compelled him to delve deeper and discover her remarkable capabilities.

> *"…my daughter showcased her ability to adapt and survive during the restriction by independently talking and taking care of herself, which she has never done before. We were surprised to see her helping her mother with cooking rice and performing simple household tasks.*

> *Her actions not only decreased my stress but also highlighted her capabilities…" (C7,Caregiver)*

Family communication involves the interaction of family members through messages, and effective communication becomes even more crucial during times of crisis and hardship. It enables a deeper level of understanding among family members, facilitating the sharing of information and support in difficult circumstances.

An effective small community for sharing information through social media and technology.

Furthermore, the key informants in this study were participants who experienced inflection. The study consisted of six blind participants and one participant with physical impairment from various regions of Thailand. Due to the peak inflection rate at that time, in this case, we conducted the two-and-a-half-hour focus group via an online setting with the Zoom application. During the session, participants shared their challenges in their infection periods and discussed how online communication and social media platforms aided their survival.

Interestingly, blindness was not a primary difficulty for blind individuals when contracting the infection. Instead, they faced confusion due to the lack of clear and relevant preliminary healthcare information from primary healthcare staff that didn't align with the reality.

"…I am so sad for any confusion caused it appears that when I called the Covid Hotline, they informed me that If I needed to serve free primary healthcare service, I should return to my domicile, where located in a remote area, but I live in Bangkok for several years … This advice did not make sense in my situation…" (P24, PWDs.)

Meanwhile, P23, a woman with a physical impairment, also shared a similar experience of receiving confusing information. Her result from the ATK (Antigen Test Kit) was positive. She called the Medicare call center to inquire about her social health insurance. Unfortunately, the response she received from the hotline made her feel disappointed.

> *"…I felt that her suggestion... it was complicated to serve primary healthcare service. I gave up and paid on my own… then connected to our Facebook community with fifteen to twenty blinds joining this group, and we always share information, life experiences, jokes, and provide counseling to one another. They advised me on how to prepare myself during the quarantine…" (P27, PWDs.)*

Besides communication through social media, particularly Facebook, using direct pop-up messages through the "Line application" also facilitates communication for blind people. The Line application is Thailand's most popular texting application, allowing users to communicate through voice messages, peer-to-peer or group chatting, and video calls without any payment. This channel allows timely and accessible communication for the blind.

> *"…we also connected via Line group or private chat if I didn't want to disturb other friends by sharing my quarantine experience or asking about identifying medications through touch or alternative methods. It was difficult for us to manage pills without assistance or the Brille labels they delivered. The healthcare service for blind people doesn't seem to be well-aligned with our actual needs. The process was unrelated to the real situation… I don't think it is effective for persons with disabilities who are infected and need self-quarantine…" (P23, PWDs.)*

Group Communication for Education: Disparities and Digital Adaptation

The majority of students with disabilities in rural areas are economically disadvantaged and have limited access to communication devices and reliable internet services. This finding highlights the division between two groups of students in the rural and urban areas: those without technical support and those with access to technical resources.

The first group comprises students in the early stages of education, particularly those aged 0 – 6 years. Early childhood education for students with disabilities (SDWs) allows them to enroll in each region's special education center. In this context, teachers play a crucial role as facilitators in delivering education, while technology serves as an assistive tool.

The unexpected closure of special education centers and the abrupt interruption of routine activities had a profound effect on students with disabilities (SWDs). The absence of a crisis response plan within the school system left both educators and communities unprepared for the challenges brought on by the pandemic. In rural areas, where many SWDs reside in distant disability centers, some of these centers had part-time school schedules to accommodate the needs of individuals. This arrangement was necessary because the parents of these students often had work commitments and lacked the time to send the children to school regularly.

> *"…The children did not have access to smartphones or tablets to participate in remote learning like mainstream students. My friends and I were at risk by visiting students at home during the outbreak, as neither the necessary devices nor reliable internet connections were available..." (E1, Educator)*

Mass communication

Delay and unequal mass communication

In remote areas, the lack of sufficient devices is the major factor hindering PWDs from accessing up-to-date information. This is in contrast with PWDs in urban areas, where there is better access to information due to improved technological infrastructure. Mass communication is commonly defined as a one-way communication. Regarding the COVID-19 situation in Thailand, the Office of Public Administration, under the Department of Disease Control, conducted official statements in 2020, These statements, coordinated by the Center for COVID-19 Situation Administration (CCSA), were considered effective means of providing health information, vaccine updates, and infection reports to the public through Thailand Broadcasting.

Regarding data collection, PWDs and their families primarily received information through mainstream media such as television, particularly in the early stage of the pandemic. However, there were some arguments highlighting the unequal distribution of information for PWDs. For instance, no specific guidelines were provided to PWDs or vulnerable groups for instruction and practical advice on preventive measures and preparedness strategies for this hardship situation.

Overall, the influence of COVID-19 on PWDs were adequately highlighted in the media or included in the government's practical roadmap. Despite voicing my concerns to the government, I did not receive a clear answer regarding the specific measures and support available for PWDs (P16,PWDs.)

Researcher 2: "…How did you voice to the government?"

> *"…Communicated through all government platforms, I remember that at that time, they promoted effective two-way communication between citizens and government. We made several attempts to connect to these platforms, but the information we received was often impractical and unhelpful. This shows that the government ignored us and there were no proactive campaigns for vulnerable groups..." (P16, PWDs.)*

Online social media and other digital platforms effectively provide information and keep connections for PWDs who can access technology devices.

Although mass communication still presents several challenges, particularly in terms of access for persons with disabilities in rural areas and the lack of direct information related to their rights, it continues to serve as a valuable tool and medium for maintaining social connections during difficult times.

> *"…Sometimes there is no direct information delivery to our members. Some of us were left alone with a radio or television at home, while some accessed information via mobile phones. Facebook is the most popular social media platform for the blind to access information such as health information, vaccine quotas, real-time situations, and government measures. Moreover, we use the "Line" application to connect and share information between members and our connections…" (C5, Caregiver)*

> *"…Since the social distancing measures, all activities had to stop, and we were stuck at home. Parents had no plan and couldn't handle the situation, and support academic work at home. Some of them can use mobile phones it's useful for monitoring students' development by call and video call, the rest of them had no technology support because of remote areas where there are no signals it's risky for teachers to visit them, but we still set the team to visited onsite because we cannot leave them alone..." (E2, Educational sector)*

DISCUSSION

This study explored the role of communication and information access among persons with disabilities (PWDs) in Thailand during the COVID-19 pandemic, through the framework of intrapersonal, group, and mass communication. In addressing reviewer feedback, this discussion integrates relevant international research to enrich the argument and reinforce the empirical insights gained from qualitative data.

Intrapersonal communication: "Living with a disability already entails significant challenges."

People with disabilities (PWDs) in both urban and rural settings view disability as a continuous and persistent challenge in their lives, reflected in their self-expression. They convey how living with a disability impacts their self-awareness and coping strategies. However, while both groups acknowledge the difficulties of disability, individuals who live in urban areas are more likely to express their struggles in a direct and confident manner. This difference is influenced by the greater access to resources, technology, and opportunities for self-expression available in urban environments. In rural areas, people with disabilities often rely on word-of-mouth communication from family members or community broadcasts, as access to modern communication tools and technologies is more limited. On the other hand, urban-dwelling PWDs are more likely to utilize digital platforms, social media, and messaging applications to share information and advocate for their needs. This aligns with van Deursen's (2020) concept of the "digital divide," which emphasizes on how unequal access to digital resources exacerbates disparities in communication and information access among vulnerable groups (van Deursen, 2020).

Urban environments, characterized by enhanced access to technology and more vibrant social dynamics, offer PWDs with greater opportunities to engage in more proactive communication. They are empowered by the ability to connect, share their experiences, and advocate for their rights through digital platforms, social media, and advocacy groups. Having experience with fighting for their rights and confronting systemic inequality, urban PWDs develop a sense of agency and resilience, drawing on both individual and collective empowerment to challenge and navigate social barriers. The empowerment gap between urban and rural PWDs underscores the need for inclusive communication strategies that consider the contextual differences in access to resources, technology, and social networks. This disparity emphasizes the importance of bridging the digital divide, ensuring that all PWDs, regardless of location, have the necessary tools to communicate effectively and assert their rights.

Group Communication: Social Capital, Family Cohesion, and Digital Networks

Group communication emerged as a central survival mechanism during the crisis, offering both tangible and intangible support. Financially, disabled people's organizations (DPOs) functioned as key brokers of social capital. Top-down and lateral communication through digital platforms such as Facebook and Line allowed for the dissemination of health updates, coordination of mutual aid, and organization of charity campaigns. This reflects Lin's (2001) theory that social capital is embedded in relational networks, as well as findings by Dobransky and Hargittai (2021), who reported that PWDs leveraged social media to sustain information flow and emotional support.

Nonetheless, relying heavily on community-led or digital solutions risks shifting responsibility away from public institutions. As Baldwin et al. (2023) pointed out, the absence of state preparedness in ensuring accessible information formats meant that civil society often had to fill a gap that should have been covered by public policy. The proactive role of DPOs, while commendable, may inadvertently obscure failures in inclusive governance.

Family communication also played a transformative role during the COVID 19 pandemic. While existing literature suggest increased familial conflict during lockdowns (Toseeb & Asbury, 2022), this study found that caregiving relationships deepened, and autonomy in PWDs was recognized and supported and mutual understanding were strengthened. This finding resonates with Baldwin et al. (2023), who emphasized that involving PWDs in the design of communication formats reduces confusion. The normalization of home-based interaction facilitated mutual understanding and role renegotiation, resonating with Sonnenschein et al. (2022), who underscored the significance of parental attitudes and adaptability during school closures.

Small community networks—particularly those created online—proved vital for bridging information gaps during infection and quarantine. Participants shared personal experiences, accessed peer support, and clarified confusing health directives. This supports the work of Dai and Hu (2022), who found that informal disability networks compensated for government communication failures, and Goodyear et al. (2021), who noted the power of digital tools in managing behavior and well-being.

Effective small community communication to sharing information through social media and technology.

In addition to the aforementioned dimensions, this study highlights the critical role of group communication through digital technology among PWDs who had access to relevant devices and platforms. As face-to-face interaction became restricted during the pandemic, community members increasingly transitioned to digital communication environments. Wu and Yu (2021) observed that social media and messaging applications such as Facebook and Line became vital tools, enabling users to maintain social connections, access timely information, and coordinate support. These platforms not only replaced physical interaction but also contributed to life-saving exchanges during quarantine periods.

Dobransky and Hargittai (2021) provided further evidence that PWDs actively engaged with COVID-19-related content across digital platforms by sharing their personal experiences, viewing pandemic-related information, disseminating such content, and engaging in interactive exchanges with others. Similarly, Goodyear et al. (2021) found that social media enabled PWDs to self-manage behaviors related to physical activity, dietary habits, and general well-being, reinforcing its value during public health emergencies. Dai and Hu (2021) further emphasized that chat applications served as central hubs for real-time communication and collaboration within disability networks, reinforcing the transformative role of digital group communication during crises.

Despite these advances, the necessity for immediate, accessible information via alternative digital channels exposed significant shortcomings in government policy and practice. Structural discrimination manifests in delayed, limited, and inaccessible communication, particularly regarding infection prevention and health service guidance. Ara and Sik-Lanyi (2022) identified critical usability issues in many official websites, including disorganized navigation structures, inadequate explanatory content, and outdated information—barriers that hinder access for users with disabilities. Additionally, Mhiripiri and Miszi (2021) highlighted that public health messaging often lacked sign language interpretation, leaving deaf individuals underserved. Effective risk communication must be timely, accurate, and presented in formats that are both inclusive and trustworthy. As Goggin and Ellis (2020) noted, successful examples—such as captioned and sign language-interpreted daily press briefings—demonstrate the necessity of accessible, multimodal dissemination strategies in fostering inclusive public health communication.

Group Communication for Education: Disparities and Digital Adaptation

The educational domain revealed stark digital inequalities. While students with medium-impact barriers managed to maintain learning via devices, those in high-impact categories (e.g., remote rural students) lost access altogether. Teachers served as communication anchors, conducting home visits and facilitating hybrid learning, reflecting the importance of educator-parent partnerships noted by Meda and Waghid (2022).

UNESCO’s (2021) matrix of education access barriers during COVID-19 is a useful analytical tool here. Inaccessible teaching methods, limited assistive technology (AT), and unreliable internet compounded the marginalization of PWDs. These findings align with Chiluba et al. (2020), who stressed the need for systemic digital inclusion policies. This underscores that while digital platforms offer opportunities, they also risk widening gaps unless inclusivity is prioritized.

However, it is crucial to critique the lack of institutional preparedness. As Acosta-Vargas et al. (2022) found, many education portals failed accessibility compliance, suggesting that digital learning was designed with normative assumptions about user abilities. The failure to incorporate universal design principles exposed PWDs to educational exclusion and demonstrates an urgent need to embed inclusivity at the design stage.

Public and Mass Communication: “Delay in formation and unequal mass communication”.

At the mass communication level, this study identified significant delays and inequalities. While official COVID-19 information was widely broadcast, it often lacked accessible formats, such as real-time sign language interpretation or plain language summaries. This finding corresponds with the global review by Armitage and Nellums (2020), who argued that inaccessible communication perpetuates exclusion.

Participants expressed frustration over impractical or confusing messages, especially via national COVID-19 hotlines and websites, which reflects Acosta-Vargas et al.’s (2022) web audit showing widespread noncompliance with accessibility standards. In Thailand, PWDs often relied on informal sources or DPOs to interpret and repackage information, mirroring findings from Avby et al. (2024) in Sweden and Baldwin et al. (2023) in the U.S.

However, those with access to smartphones and social media experienced more timely and interactive communication. Platforms like Line enabled real-time problem-solving, advice sharing, and emotional support. This adaptive strategy reinforces the findings of Cho and Kim (2022), who emphasized that digital inclusion must be supported by skills training and device accessibility.

Nevertheless, these individual adaptations should not distract from broader structural critiques. As Bjornsdottir et al. (2023) and Friedman & VanPuymbrouck (2022) argue, technological access does not guarantee equity unless paired with tailored support, content simplification, and interface accessibility. Mass communication strategies must move beyond universal delivery to embrace differentiated and inclusive engagement.

CONCLUSIONS

The communication experiences of PWDs during COVID-19 highlight critical tensions between resilience and exclusion. While group and interpersonal strategies offered strength, systemic barriers in mass communication and education exposed structural neglect. Integrating insights from international studies not only validates local findings but underscores the global nature of disability-related communication disparities.

These results reinforce the need for a multi-level, inclusive communication policy in health emergencies—one that acknowledges intrapersonal agency, strengthens local networks, ensures digital equity, and mandates accessibility in all public communications. Moreover, future strategies must go beyond reactive measures and institutionalize inclusive practices, ensuring that persons with disabilities are not only informed but actively engaged as partners in health crisis communication and planning.

Importantly, this research offers novel insights by illustrating how the intersections of communication levels—particularly intrapersonal resilience, family-based dialogue, and digital peer networks—uniquely shape the adaptive responses of PWDs in the Thai context. Unlike studies that focus solely on technological access or policy gaps, this study foregrounds the lived agency of PWDs and their informal networks as active mediators of health communication. The findings call for a more participatory model of crisis response that recognizes PWDs not only as vulnerable recipients but as contributors to resilient communication ecologies.

RECOMMENDATIONS

1.Strengthen the Role of Disabled People's Organizations (DPOs)

Given the essential role DPOs played in disseminating information, organizing aid, and supporting their members, policies should formally recognize and fund these organizations as key stakeholders in crisis communication and disaster preparedness.In rural areas, where access to technology may be limited, facilitating interaction among PWDs through peer-to-peer communication becomes crucial. Local stakeholders should actively engage and communicate accurate information to PWDs in these areas.

2.Enhance Digital Accessibility and Inclusion

Investment in digital infrastructure must be accompanied by the development of accessible platforms and user interfaces that comply with universal design principles. Furthermore, digital literacy programs specifically tailored for PWDs and their families should be expanded to ensure equitable access to telecommunication, e-learning, and health services.

3. Integrate Family-Based Communication Support in Social Policy

The study highlights the potential of family dialogue in fostering resilience. Social support policies should consider interventions that strengthen intra-family communication, including family counseling, caregiver training, and flexible education programs that promote home-based learning in inclusive ways.

4. Ensure Educational Equity in Emergency Contexts

Preparing inclusive e-learning contingency plans that address infrastructural, pedagogical, and technological barriers faced by students with disabilities is equally important.

5. Foster Participatory Crisis Response Planning

This study underscores the agency of PWDs and their networks in navigating the pandemic. Future public health planning should move beyond viewing PWDs as passive recipients of aid and instead involve them as active contributors to the design of inclusive communication systems and emergency services.

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Original Research Article

Challenges, Promoting Factors of Disparity and Coping Strategies for Women Employees with Disabilities: Evidence from Malawi

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ABSTRACT

Background: Persons with disabilities, particularly women, often face discrimination and marginalization. This undermines the achievement of Sustainable Development Goals (SDGs) that promote equality and equity. Therefore, identifying the underlying factors and ways to ameliorate such challenges is imperative for ensuring equality and inclusiveness.

Objectives: The study's main objectives were to identify the challenges faced by women with disabilities in their workplaces in Malawi, promoting factors that cause such challenges and the coping strategies adopted in overcoming such challenges.

Method: The present study adopted a qualitative research design. The participants in the study were forty-five working women with disabilities identified through purposive sampling. Data were collected through interviews and analyzed thematically.

Results: The results revealed that women employees with disabilities face diverse challenges, such as stigma and prejudice. The factors that promoted such challenges included the gender, marital status, and minority status of these women. The study also revealed self-confidence and withdrawal as different coping strategies adopted by these women.

Conclusion: The current study demonstrated the need to increase awareness, support, and targeted intervention services for women with disabilities in the workplace, especially women in a volatile society such as Malawi, to enhance social and cultural inclusiveness.

Contribution: The study created greater awareness of the need to provide an enabling environment and social security for women with disabilities in the workplace.

Keywords: challenges, coping strategy, disability, promoting factors, women, workplace

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INTRODUCTION

Globally, the population of people with disabilities is estimated to be one billion (approximately 15 per cent of the world's population), of which approximately 80 per cent are of working age (World Health Organization, WHO, 2021). In developing countries, the percentage of the population living with disabilities is high because of the prevalence of poverty. Several studies (Braithwaite & Mont, 2009; Mont & Cuong, 2011; Trani & Loeb, 2012; Mitra et al., 2013; Eide & Ingstad, 2013) have shown a relationship between poverty and the risk of disability, stating that poverty exacerbates malnutrition, poor health care, a polluted environment, unsafe water, and poor sanitation among poor households. About 86.5% of the population of Malawi, a nation in South-Eastern Africa, lives in rural areas, making it one of the least developed nations in the world. Like many other low-income nations, Malawi relies heavily on agriculture, with the industry accounting for around 30.2% of the country's GDP (Pauw et al., 2011).

More research needs to be conducted on the nature of informal work in urban regions and business districts in Malawi, concentrating on the rural realities of work in Malawi, particularly farming (Hazarika & Sarangi, 2008). In 2020, approximately 77.79% of Malawi's population between the ages of 15 and 65 was in the labor force (Statista, 2021). This translates to 3.5 million individuals working in Malawi, most of whom are in the informal sector, making it challenging to calculate the nation's unemployment and under-employment statistics. Instead of focusing primarily on people with impairments, they support young people as they enter a formal economy. Malawi's population is young, with a median age of 17 years (Statista, 2021); as a result, the country's development strategies place employment—present and future—at the center (Chinsinga & Chasukwa, 2018).

The challenges faced by people with disabilities are similar to those faced by many other jobseekers. A few obstacles include the need for work-based learning opportunities, high-quality skills, and professional development programs. However, women face specific gender-based obstacles, such as continued informality (Khan, 2020) and conceptual issues with private sector development programs (Quak & Flynn, 2019).

In response, previous governments in Malawi have introduced legislation that promotes the inclusion of people with disabilities, such as the 1971 Handicapped Persons Act, which led to the Malawi Council for the Handicapped (MACOHA) and the 2006 National Policy on the Equalization of Opportunities for Persons with Disabilities, long before the ratification of the UN Convention. The United Nations CRPD, which Malawi ratified in 2007, includes specific instructions for supporting people with disabilities in their work and employment, as contained in Article 27. However, practice limits the enactment of CRPD commitment. Equally, the Convention led to Malawi's ratification of the International Labor Organization (ILO) Convention 100 (on equal pay) and 111 (on discrimination), both of which are aimed at promoting workplace protections and rights of those with disabilities. In 2012, the Malawian government passed the Disability Act, which strengthened Malawi's commitment to the rights of people with disabilities. This led to the creation of the National Disability Mainstreaming Strategy in 2018.

Despite this, employment rates for people with disabilities continue to dwindle, particularly in the districts of Lilongwe and Blantyre. Due to their extensive economic wealth, Lilongwe and Blantyre districts are invariably Malawi's two biggest cities. The Lilongwe 2018–2023 National Disability Mainstreaming Strategy and Implementation Plan was created in response to evidence of poor representation of the primarily informal impaired workforce in cities. This supports the rationale behind selecting these cities for the current study (Remnant et al., 2022). However, according to data from the 2018 census, 12% of Malawi's dynamic labour force comprises people with disabilities (National Statistical Office, 2019), with a ratio of 47% for females and 53% for males. Women with disabilities in Malawi have experienced various types of discrimination. They are frequently at a higher disadvantage than their male counterparts (NSSP, 2018) because of their inability to find formal employment caused by restricted economic possibilities and further exacerbated by obstacles such as discrimination, poor accessibility, and lack of acceptable accommodations.

Furthermore, the population of women with disabilities in Malawi is approximately 937,536, representing 6.2 per cent of the total population (National Statistics Office 2018). These women are at a higher risk of marginalization given that Malawi has a high rate of gender inequality. According to the United Nations Gender Inequality Index (GII), Malawi ranked 173rd among 188 countries (USAID, 2015). Similarly, Malawi was positioned 142nd out of 162 countries and exhibited the third highest gender inequality index. In addition, the SINTEF 2017 survey report showed that 58 per cent of persons with disabilities, especially women, were unemployed. The remaining percentage often encounters discrimination and biases, which impede the achievement of UN sustainable development goals. Sustainable Development Goal Eight aims for decent work for all and inclusive economic growth. As a result, a large number of disabled women work in informal, low-paying jobs or risk being unemployed, as well as living in poverty. For instance, the Federation of Disability Organizations in Malawi (FEDOMA) discovered that only 14% of women with impairments were employed.

According to a UN Women study, which supports the claim mentioned above, women with disabilities in Malawi experience greater rates of abuse and have less access to support services and the legal system (NSSP, 2018). As a result, numerous organizations in Malawi have worked towards promoting the rights and empowerment of women with disabilities. Among such organizations are the Malawi Association of the Deaf Women (MADW) and Disabled Women in Development (DIWODE). However, employed women with disabilities often face discrimination in society and the workplace. Hence, understanding the challenges and coping strategies of women with disabilities at the workplace is relevant to achieving SDG 8 (decent work and Economic Growth) and SDG 5 (gender equality).

The existing literature (Ababneh, 2016; Maja et al., 2011; Noor et al., 2018; Ta et al., 2011) has analyzed various dimensions of employability among persons with disabilities. However, there is limited emphasis on the challenges faced by women living with disabilities in Africa, especially in Malawi. Although previous studies, such as Ta and Leng (2013), have examined the challenges faced by persons with disabilities, they primarily focused on the challenges faced in gaining employment among those with disabilities.

Thus, there is a paucity of studies on the challenges faced by women with disabilities in their workplaces, promoting factors, and coping strategies adopted in the course of such challenges. This study aims to fill this gap by investigating the challenges faced by women with disabilities at their workplace in Malawi, the promoting/triggering factors, and the coping strategies adopted to overcome such challenges. Based on the review of the literature, the researchers sought to answer the following research questions:

1. What are the challenges faced by working women with disabilities in Malawi?
2. What factors promote the challenges faced by working women with disabilities in Malawi?
3. What coping strategies have been adopted by working women with disabilities to keep aloof in their workplace?

METHODS

Setting

This study was conducted in the central business districts of Lilongwe and Blantyre. Both districts are cities with a combination of urban, semi-urban, and rural societies. The districts host many NGOs and private organizations, and the civil service has various ministries operating in both districts at the administrative and technical levels. Furthermore, the two districts have government-owned universities, colleges, and training centers. Lilongwe and Blantyre also have vocational rehabilitation and skills training centers owned by NGOs and private organizations. The two districts have officials/representatives of Malawi's various disabled persons' organizations (DPO) and those working in civil service, the private sector, and the mainstream disability sector. For demographics and workplaces of respondents, (see Table 1 and Fig.1).

Table 1: Demographics

Age		25-55 years
Mean Age		37.40 years
SD		6.33
Gender	Females	45
Marital status		
Single		28 (62.2%)
Married		12 (26.7%)
Divorced/Widowed		5 (11.1%)
Educational Qualification		
Diploma Certificate		13 (28.9%)
Junior Certificate of Education		8 (17.8%)
Bachelor’s Degree		10 (22.2%)
Malawi School Certificate of Education		14 (31.1%)

Of these, the mean age of the respondents was 37.40 (SD =6.33). The majority (62.2%) were single; 26.7% were married; and 11.1% were divorced or widowed. Despite living with disabilities, the respondents attained some level of education. Regarding educational qualification, 28.9% of the respondents had diploma certificates, 17.8% had a Junior Certificate of Education (JCE), 22.2% had bachelor’s degrees, and 31.1% had a Malawi School Certificate of Education (MSCE).

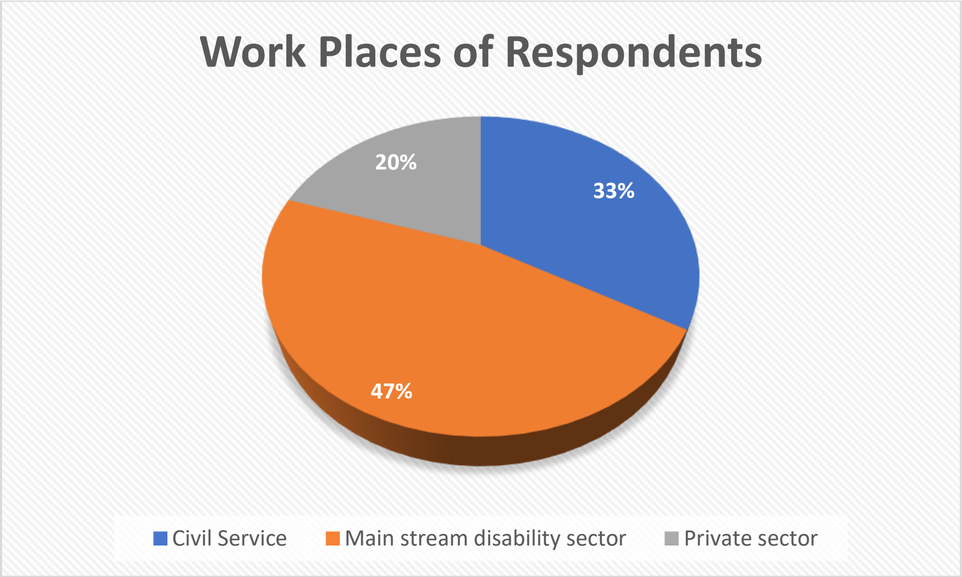

Figure 1: Work Sector of Respondents

The majority of the respondents (47%) worked at the Malawi Council of the Handicapped and various organizations for disabled persons, such as Malawi Against Physical Disabilities. In comparison, approximately 33% and 20% of respondents worked in the civil service and private sectors, respectively.

Study design

The study adopted a qualitative research approach because the researchers were interested in understanding the challenges from the viewpoint of individuals with disabilities. This is pertinent because the qualitative research approach provides a comprehensive knowledge of human behaviour and associated factors (Lewis, 2015). In-depth interviews and a focus group discussion design were applied in the management of data collection for the study. This gave the researchers valuable insight into respondents' experiences, opinions, and perceptions, which is apt for understanding the nuances of human behaviour and subjective experience.

The respondents were 45 working women with different disabilities in the Lilongwe and Blantyre districts of Malawi. Seven (7) had PW Albinism, eight (8) had PW blind or visual impairment, two (2) had PW deafness, and twenty-eight (28) had physical disabilities (See Table 2).

Table 2: Varying Degrees of Participants' Disabilities

Disability	Frequency	Percentage
Albinism	7	15.6 %
Blind/Visually Impaired	8	17.8%
Deaf	2	4.4%
Physically Disabled	28	62.2%
Total	45	100

The study sample was selected from among working females with disabilities in the Lilongwe and Blantyre Districts. The sample size was calculated using the Raosoft online sample size calculator with a 5% margin of error, 95% confidence level, and 50% response rate. Thus, the sample size of 45 used in the current study was greater than the estimated sample size of 44. The population considered was 49 women with disabilities employed in the civil service, private, and mainstream sectors in Lilongwe and Blantyre Districts of Malawi. This sample size method has been used in most qualitative studies (e.g., Abdulsaum et al., 2023). The participants were recruited from the private, public, and mainstream sectors of Malawi with the assistance of DPOs representing different disability organizations in Malawi. Malawi is a signatory to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), hereto legally adopt the general conceptualization of disability to include people with physical, intellectual, mental, and sensory impairments, in conjunction with contextual and environmental factors that impede their full participation in daily life (UN, 2006).

Data were collected using a face-to-face In-Depth Interview (IDI) guide comprising five unstructured questions. The questions in the interview guide focused on the challenges faced by working women with disabilities, the factors fuelling these challenges, and the coping strategies they adopted in their workplace. The interviews were scheduled to last 10-15 minutes with little leverage for participants with more profound experience and valuable information and were willing to extend the discussion.

Thematic analysis was applied to analyze the data collected. This is because the qualitative study used face-to-face interviews (Williams & Moser, 2019). First, interview responses were recorded after permission was granted from the participants. After the interview, the data were translated from the original recordings (Chichewa) to English because most interviews were conducted in the native language (Chichewa). This involved careful editing and scrutiny of the data recorded in the interviews to ensure data accuracy (Kothari, 2004). In addition, the data were coded to identify fundamental structures and factors such as words, sentences, and meanings. This is pertinent because coding links data collection and interpretation of its central (parent) and subcodes, whereby the latter reflects the main related idea in meaning (Lewis, 2015). To achieve this, MAXQDA software was used for the coding process, whereby the transcribed interview data were imported into MAXQDA as a Word document. The software makes it easy for researchers to extract direct quotes from the participants on the issues that they thought were central to the focus of the study.

The researchers went through the interview text paragraph-by-paragraph and ascribed tags, labels, or codes to the text based on understanding what the participants were portraying. However, these codes were divided into central (parent) and subcodes, as Lewis (2015) identified. These codes were then grouped to identify themes emerging from the data. Thus, these themes invariably became the yardstick or basis for the presentation and discussion of results.

Trustworthiness

The robustness of the current study hinges on the fact that the study findings follow the tenets and criteria of applicability and dependability (implying that the researchers strived to make future research replicable through a detailed research design on the tools utilized in data collection interpretation and analysis), transferability (achieved in the present study through an intricate background of the study area carried out in Lilongwe and Blantyre, which are Malawi's central business districts, thus allowing the extrapolation of the research findings to similar study areas), conformability (implying data collection and analysis objectivity, through safe-keeping of data collected for replication and validation of the findings when required by other researchers), neutrality, and credibility (implying that the study inquiry was conducted in a way that the participants were described correctly and identified. Thus, the qualitative methodology adopted for the study was stipulated, involving face-to-face interviews of the participants selected through purposive sampling, ensuring consistency as postulated by Denzian and Lincoln (2011) and Shenton (2004) for data collection and analysis. Purposive sampling was used because the study centered on a specific domain (female employees with disabilities). According to Palinkas et al. (2015), purposive sampling aids select participants that are most likely to yield appropriate and useful information by identifying and selecting cases that will use limited research resources effectively. Thus, this sampling method has been used in qualitative studies (Kelly, 1994; Miles & Muberman, 2010).

Ethical considerations

Before data collection, participants were informed about the aim and purpose of the study and what the intended findings would be used for. Those who consented to participate provided signed consent forms. Permission to conduct the study was sought from the Ministry of Gender, Children, Disability, and Social Welfare (protocol number ADM/02/014). This study followed all procedures under the guidelines for ethical standards of the responsible committee on human experimentation (institutional and national) and the Helsinki Declaration of 1975, as revised in 2013.

RESULTS

The following themes emerged from the data: women with disabilities as a minority population in the labour force; absence/lack of access to compatible facilities in the workplace; social stigma and uninformed attitudes towards women with disabilities as factors promoting the plight of women with disabilities; gender inequality in public and private institutions as hurdles against women with disabilities; the perennial and multidimensional poverty in the developing nations as a threat to working women with disabilities; and self-resilience and supportive network as a coping strategy for working women with disabilities.

Women with Disability as a Minority Group in the Labour Force

Although women with disabilities in the workforce appeared to be a minority in the Lilongwe and Blantyre districts, matters involving their rights capture little or no attention. Even though these rights and privileges are obvious within the workforce and mainstream society, they are ignored, following the minority status of women with disabilities in the labour force.

> *"Male domination in the society-patriarchy common among the African population equally plays out in the circle of people with disabilities. For instance, male colleagues appear to be treated with preference compared to female employees with disabilities in the workplace. This can be observed when we have common and similar challenges in the place of work, such as promotion issues."*

> *"Gender-specific rights for women with disabilities need more attention, as they face unique challenges; efforts to promote gender equality often overlook the intersection of gender and disability, and this automatically hides the population of the women with disabilities from the public attention"*

Due to a lack of awareness and poor attitudes towards disability, respondents expressed how they were exposed to various misconceptions and prejudices in their workplaces:

> *"In my place of work, the issue of disability is totally misunderstood due to poor awareness among the co-workers. It is even worse when it involves genders, such as ours, who are graded as second-class citizens. Females in Malawi are technically treated as second-class citizens, and when one is involved in one disability issue or the other, she is unconsciously excused in public places with the view that she is a liability to society even in the place of work".*

> *"Both in the public and private sectors of employment, the gender discrimination and patriarchal issues are systematic especially as they affect women with disability in the workplace. Access to opportunities such as loans and support in time of needs are unnecessarily difficult for women with disabilities in their institutions of employment due to the stringent measures, which are gender stereotyped."*

The poor awareness of people with disabilities, and women in the workforce specifically, often creates the problem of a blanket approach to the issues of women with disabilities even when there is the slightest opportunity to manage the issue in different contexts, as the people handling this do with some complexities and segregations. Due to the poor awareness of people with disabilities, even people at the helm of affairs in the workplace ignore or treat with kid gloves the issues affecting women with disabilities in the workforce.

> *"In the workplace, the needs of women with disability are not usually the same with even the male fellows with disability; however, in the work place the cases involving women with disability are treated anyhow in comparison with their male colleagues and even other employees in the workplace."*

Absence/Lack of Access to Compatible Facilities in the Work Force

For women with disabilities in the workplace, certain facilities and conditions are necessary to inspire their jobs. These include accessible infrastructure, such as ramps, elevators, and wider doorways. Administratively, the organization ought to create a conducive atmosphere for women with disabilities to easily operate in the system without discrimination and abuse. As such, management of public and private organizations has the duty of training co-workers and management of disability awareness and etiquette to handle employees' grievances as well as human rights violations; however, the reality is the opposite. In most cases, management in the private and mainstream government labour force does not pay attention to these observations as the facilities in these places lack evidence of accommodating people with disabilities.

> *"Very few places show signs of accommodating people with disabilities; the few of these I have observed have sufficient moving space around the working environment: wider doors, wider corridors, spacious toilet room etc. These allow women with disabilities working in these places with the mobility and independence needed to comfortably navigate the environment and operate without much help from others".*

> As stated by another participant:

> *"women with disabilities in the workplace encounter limited access to assistive devices and technologies necessary for efficient job performance".*

Policy-wise, public and private employers in Malawi are virtually out of tune with the current global interests and agenda concerning people with disabilities, which is reflected in the infrastructural design of the workplace and the management of the employees' relationship policy. In most private and public institutions employing people with disabilities, the infrastructure lacks disability-friendly design and assistive technologies and other necessary facilities, particularly for women with disabilities. Likewise, most public and private institutions in Malawi lacked policies on the orientation of employees regarding their relationship with people with disabilities in the workplace.

> *"There is a need for training for co-workers and management on disability awareness and etiquette as this is lacking among the public and private institutions in Malawi"; "Lack of awareness about disabilities by others who are not leads to misconceptions and prejudices regarding their capabilities."*

> *"Due to the increasing prejudice against people with disabilities, women in particular are becoming vulnerable to discrimination and misconception in the workplace, leading to deprivation and selected injustice by some colleagues who have phobia against disability"*

> *"My personal encounter with some top management officials in my organization of employment made me to realize that the unguarded relationship between people with disabilities especially women with disabilities and other employees really put them at the risk of individual differences in the workplaces in Malawi, which can be negative against women employees with disabilities"*

Social Stigma and Uninformed Attitude towards Women with Disabilities as Promoting factors to the plight of women with disabilities in the workforce

The problem of people with disabilities is compounded by how the people around them in the family, community, and other public places relate to them. Among developing nations such as Malawi, social stigma is an enduring factor in dealing with people with disabilities. While the problem of social stigma is anchored to an uninformed attitude towards people with disabilities, an uninformed attitude is the product of poor and absence of public awareness about the uniqueness of people with disabilities and, in the long run, results in an endless cycle of stigma against people with disabilities in public places and, more often, in workplaces. Women with disabilities are treated with prejudice as part of the social stigma they face in the workforce.

> *"Much as I have worked in both public and private sectors, where one would expect that there is a great understanding of disability and that stigma and prejudice should not exist, it is a general opinion of many, even at my workplace, that persons with disabilities are difficult people"*

Owing to the enduring pressure of social stigma against people with disabilities among the population, prejudice and negative attitudes towards people with disabilities in most working settings are pronounced in the behaviors of their work colleagues. Women with disabilities in the workplace are surrounded by a negative impression of the majority of people working with them, which always surfaces in times of misunderstanding and individual differences.

> *"Many of my co-workers and my bosses have a negative attitude towards me, some being so open about it and expressing it in public and others concealing it as much as possible."*
>
> *In addition, one of the participants stated, 'Many of my colleagues and superiors displayed a negative attitude towards disabled individuals, sometimes in public and other times hidden.'*
>
> *"Despite working in the mainstream disability sector, I've seen the prevailing opinion that persons with disabilities are difficult to work with, even within my workplace".*
>
> *"Women with disabilities especially the single ladies like us are treated with some level of disrespect compared to our male counterparts. This is evident in the times of seeking assistance financially and otherwise, which may require some protocols and trust. This is when you will discover that even your work colleagues do see you as lower-class citizens with little or no value depending on the type of disability you have".*

Gender Inequality in the Public and Private Institutions as a Hurdle against Women with Disabilities

Having faced the challenges of gender inequality entrenched in social institutions such as the family, education, economy, politics, and employment, women with disabilities in the workplace are already trapped in a cycle of demeaning treatment.

> *"Because of the Gender inequality concerning education and qualifications, the challenges women with disabilities face concerning career advancement is more complex and complicated in Malawi."*

Efforts to promote gender equality often overlook the intersection of gender and disability, which is a chronic problem for the freedom and liberty of women with disabilities. Gender-specific rights for women with disabilities require more attention as they face unique challenges.

> *"Gender-specific rights for women with disabilities need more attention, as they face unique challenges; efforts to promote gender equality often overlook the intersection of gender and disability".*
>
> *"In the workplace, women with disabilities are not considered for technological assistance such as provision of specialized equipment for the visually impaired persons, people with hearing impairment and those with mobility impairment who are almost competing with their colleagues in the place of work. In this same condition, promotions are considered with unfriendly measures to women with disabilities"*
>
> *"In my workplace, when it comes to the benefits beyond our salary, only men and other people who have connections are dominating in the place of work and do not allow us who look helpless in the face of corrupt system to access opportunities. There are no specific policies providing women with a disability advantage for promotion, study opportunities, and other benefits in the place of work".*

The Perennial and Multidimensional Poverty in the Developing Nations as a Threat to Working Women with Disabilities

In Malawi, private and public institutions hosting workers to different degrees lacked extant humanitarian policies concerning people with disabilities. Although people with disabilities in the workforce, especially women, need disability-friendly facilities to perform effectively in the workplace as is obtainable in developed nations, such facilities are almost absent in Malawi. This is due to the poor infrastructure and facilities in the workplace.

> *"Disability-friendly facilities are often inadequate due to lack of funding, leaving many needs unmet; primarily, women with visible disabilities and mobility impairments tend to use these facilities though lack of awareness limits utilization of these facilities."*

Compelling yet disability-friendly workplace policies and infrastructure are lacking in most institutions in Malawi. Female employees with disabilities in Malawi struggle with facilities and workplace policies, ignoring their conditions and rights. As one of the participants stated:

> *"Basic rights such as safe working conditions and protection against discrimination are recognized but not always upheld because of limited resources to support having the necessary things in the workplace."*

> *"Facilities are often inadequate due to lack of funding, leaving many needs unmet at the workplace." "Another challenge is limited resources and funding; this hinders the creation of disability-friendly work environments".*

> *"Due to poor policy infrastructure in both public and private institutions in Malawi, especially as it affects women with disability, women with disability in workplaces are facing discrimination and abuse. In my own case, my experiences in the hands of my male colleagues always depict the hopeless situation of women with disabilities in this part of the world….. they can treat you as if you have no value because of your condition and, no existing policy to control the excesses of those who have phobia against people with disabilities"*

Self-Resilience and Supportive Network as a Coping Strategy for Working Women with Disability

Women with disabilities over the years do form domineering attitudes against discouragement. In a setting in which they maintain some level of constant communication with their colleagues, they form a sustainable network to meet their needs and encourage each other. In the case of female employees with disabilities in Malawi, the dominant culture of self-resilience and supportive networks among people with disabilities has become a systematic landing gear. As one of the participants stated,

> *"The women with disabilities in the workplace cope by relying on personal determination and resilience to overcome workplace challenges; even though our colleagues create the impression that we are miserable because of our condition, seeing a fellow with disability and self-confidence inspires us and keep us moving"*

> *"I just chose always to ignore whatever challenge I face, regardless of the degree of the challenge or its effects. I just let it out. I have reaped no positive outcomes for many years after using other strategies like reporting or trying to fight for my rights by sensitizing the people, among others".*

Among female employees with disabilities in Malawi, there is a gradual and formidable network that has helped stabilize them in the workplace due to common experiences in the workplace and encouragement of one another to understand their peculiar situation in the workplace and society due to their condition. According to one of the participants,

> *"The female employees with disability in the workplace also form supportive networks within the workplace which help them navigate difficulties facing them in the workplace."*

DISCUSSION

The present study investigated the challenges, promoting factors, and strategies of female employees with disabilities, with a focus on workplace relationships and infrastructural and institutional factors forming the major thrust of the study. Following the thematic analysis of the collected data, the study captured the dimensions of the challenges, the promoting factors, and the coping strategies adopted by working women with disabilities in the workforce. The findings revealed that women with disabilities encounter various challenges in the workplace, such as stigma and prejudice, a lack of facilities and infrastructure for people with disabilities, and exclusion from the benefits of working in different institutions where they have been employed. For instance, the impact of stigma and prejudice highlights the challenges and discriminatory treatment that working women with disabilities encountered in their workplaces. Consequently, these discriminatory attitudes contribute to lower confidence levels, difficulties in adapting to the work environment, and potential limitations in accessing work-related benefits. Previous studies (Friedman, 2020; Ismail & Mujuru, 2020; Morwane et al., 2021; Remnant et al., 2022) have shown that individuals with disabilities face many challenges such as difficulty accessing social services, limited education and skill development, lack of awareness and training, and employment and discrimination challenges. According to the SINTEF (2017) survey and NSSP (2018) findings, women with disabilities are the most vulnerable to workplace marginalization and discrimination. Despite many Acts and legislations on disability, such as the Disability Act of 2012, Malawi Council for the Handicapped (MACOHA), the 2006 National Policy on Equalization of Opportunities for Persons with Disability, National Disability Main Stream Strategy and Implementation Plan, and ratification of the UN Convention on supporting people with disabilities in work and employment against discrimination put in place, the desired results are far-fetched. Thus, these findings emphasize the need to address and mitigate these challenges to ensure fair treatment and equal opportunities for women with disabilities in the workplace. However, participants' responses generally revealed that many needed more knowledge regarding their rights and the processes for claiming them, which hindered their ability to effectively assert their needs. Consequently, reporting instances of human rights violations to authorities was impeded by fear of reprisal from the individuals being reported, as well as the perceived slow or inadequate response from relevant authorities, a situation constantly altering global efforts to eradicate discrimination and maltreatment against people with disabilities (Eide & Ingstad, 2013; MacLachlan et al., 2014).

Furthermore, the study's findings revealed some perceived factors contributing to discrimination against working women with disabilities, such as social stigma, gender inequality, and lack of workplace policy to protect women with disabilities in the workplace. More importantly, the problem of uninformed attitudes among people related to women with disabilities in their workplaces further complicates the challenges women face. Following the poor awareness or even lack of awareness in the workplace about women with disabilities and their peculiarities, most of their colleagues hold grudges against them based on prejudice informed by mere labelling of the group by other people, such that they are commonly seen as difficult people to work with. Institutionally, the prevailing poverty in the system, which has virtually encroached on the policy process, has encouraged unhealthy work environments for women with disabilities. This reflects the poor infrastructural design and outlooks, typically anti-disabilities in nature, and the absence of workplace orientation involving the knowledge and understanding of women in the workplace with disabilities. Previous studies (Fide & Ingstad, 2011; National

Statistics Office, 2019) aligned with the perceived promoting factors revealed in this present study and asserted that these factors are detrimental to actualizing equity and inclusiveness in every sphere and sector of the economy concerning people with disabilities. These perceived promoting factors are inimical to the goals of establishing the Malawi Disability Act of 2012 and the UNCRT. Other perceived triggers of discrimination against women with disabilities in their workplace include societal attitudes and stereotypes, limited education, limited economic opportunities, and inadequate legal protection (MacLachlan et al., 2014). Thus, there is a need for relevant authorities and NGOs saddled with the responsibility of promoting the rights of people with disabilities to reinvigorate their activities in line with the present reality.

However, the findings revealed that the respondents adopted different coping mechanisms in confronting the challenges, including withdrawal from free interactions with colleagues due to abuse and social stigma as a coping strategy, signifying social detachment with little verbal communication. The findings show that women with disabilities in the workplace are unconsciously subjected to mental trauma by their colleagues, following the prevalence of prejudice and other elements of discrimination and abuse. Equally, women have gradually adapted to these challenges by confronting them squarely, irrespective of their disabilities, ignoring the expectation of being treated equally with people without disabilities. This, by implication, has amounted to self-confidence and optimism over time as coping strategies. However, in some situations, women seek redress momentarily by complaining to authorities when faced with challenges in the workplace. Thus, adopting a proactive and common approach to coping behaviour decreases the emotional and psychological trauma associated with PWDs. This aligns with extant studies showing that proactive behaviour toward task-oriented issues decreases depressive symptoms (Penninx et al., 2013; Rao & Chen, 2022). This shows that, to navigate against discrimination in the workplace by working with women with disabilities, they employ some of these measures to stay aloft (Fumey, 2017; Chirwa et al., 2019). For example, previous studies (Braathen &Kyam, 2008) aligned with this finding that advocacy through assertiveness and confidence and building support networks through constituted authorities and NGOs can be effective coping strategies against discrimination and seeking redress. However, coping strategies employed by people with disabilities may be influenced by individual factors such as the type and severity of the disability, personal strengths, and available resources. These findings underscore the importance of establishing a supportive framework to protect working women with disabilities and promote their rights. Further research in this direction is needed to explore the effectiveness of these provisions and identify additional measures that can be implemented to foster a safe and empowering work environment for women, thereby enhancing job satisfaction and overall well-being.

Limitations of the Study

Although the study's findings provide valuable insights, it is important to acknowledge the inherent limitations of this research, which may influence the validity and generalizability of the findings. Potential constraints include limited sample size, geographic focus, and the subjective nature of self-reported experiences. These factors may affect the depth of insights gained and the applicability of the conclusions drawn. Recognizing these limitations helps to better navigate the complexities of the subject, which helps provide a more nuanced understanding of the unique experiences of these women within the Malawian socioeconomic environment.

CONCLUSION

This study highlights the challenges and coping strategies of employed women with disabilities in workplaces in Malawi. The findings show that the major challenges women face are stigmatization, prejudice, and low wages. Other challenges include exclusion from staff development training and a lack of facilities and infrastructure for people with disabilities. Notably, most respondents showed depressive symptoms, such as withdrawal, little socialization, and verbal communication. However, participants developed self-confidence and optimism over time as a coping strategy and sought redress through complaints to the constituted authorities. Hence, there is a need for increased awareness of people with disabilities to understand their social and cultural constructs. The findings of the study eventually project the need for the Malawian government to promote equity and inclusion to improve the working conditions and general welfare of people with disabilities, particularly women, through policy measures and support services. Equally, the study's findings have shown the need to ensure that employees are well-informed about their rights, including the procedures for reporting violations, which can be achieved by disseminating comprehensive job descriptions and workplace policies, explicitly outlining employees' rights, and the mechanisms for addressing violations. This study suggests that implementing sensitization and education programs within the workplace can further enhance employees' understanding of their rights and empower them to assert their needs.

POLICY RECOMMENDATIONS

The study’s findings highlight the urgent need for targeted educational and developmental interventions. Thus, it is essential to recommend policy improvements to foster an inclusive work environment. Policymakers should prioritize the development of comprehensive disability inclusion strategies, including mandatory training of employers on accessibility and diversity. Furthermore, establishing partnerships with local organizations can facilitate mentorship programs, providing women with disabilities with the tools and confidence they need to navigate their careers effectively. These recommendations aim to create a supportive framework that addresses existing disparities and promotes the advancement of women with disabilities in the workforce. By prioritizing these recommendations, researchers can inform more effective policymaking that promotes equitable employment opportunities and, ultimately, strengthens the workforce in Malawi and similar contexts globally.

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Ethical Approval: Ethical approval was obtained from the appropriate ethics committee. All procedures followed were under the ethical standards of the responsible committee on human experimentation (institutional and national) and in accordance with the Helsinki Declaration of 1975, as revised in 2000 (5).

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Original Research Article

Strategies for Fostering Inclusive Early Childhood Education for Children with Communication Disorders

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ABSTRACT

Purpose: Education fundamentally involves acquiring valuable knowledge, skills, values, and dispositions. With over 85% of brain development occurring by the age six, appropriate care and stimulation during these years are essential. Inclusive early childhood education ensures equitable learning opportunities for all children, including those with communication disorders. Special educators, rehabilitation professionals, and parents are crucial in empowering and supporting these children. Hence, the researcher aims to study the strategies for fostering inclusive early childhood education for children with communication disorders.

Method: A descriptive survey method was used, using the 'Inclusive Education Strategies Test' developed by the researcher to assess these strategies. One seventy-thirty rehab professionals working in the special education field were selected using snowball sampling techniques, and data were collected via Google Forms: percentage, mean scores, and one–way ANOVA were used for analyzing the data.

Results: The study revealed that early intervention, professional training, and effective inclusive teaching practices are essential for supporting children with communication disorders. The significant impact of multidisciplinary collaboration and field expertise emphasizes the need for targeted professional development and resource allocation to enhance educational outcomes.

Conclusion: The study underscores the necessity of continuous professional development for educators and therapists to ensure they be updated with the most current knowledge and skills to effectively support children with communication disorders. It also highlights the need for increased funding and resources to address the challenges identified, such as inadequate assistive technology and insufficient training opportunities.

Keywords: Strategies, Fostering, Inclusive Early Childhood Education, Children with Communication Disorder.

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INTRODUCTION

Investing in education is pivotal for holistic national development, particularly in a diverse and populous country like India. Recognizing the significance of inclusive education, India has made substantial progress in enhancing educational access for individuals with disabilities. This is achieved through various institutions, including special schools, mainstream schools, and inclusive schools. As per Census 2011, India has 26.8 million PwDs, constituting 2.21% of the total population. Of these, 15 million (55.89%) are men, and 11.8 million (44.11%) are women. The term "Divyangjan" encompasses individuals with diverse disabilities, such as impairments in hearing, speech, mobility, vision, mental health, intellectual abilities, cerebral palsy, and multiple disabilities. As per the UDISE 2020-21, India manages over 1.489 million schools, employs 9.507 million teachers, and educates 265.2 crore children. Among these students, 1,841,997 children with disabilities are enrolled in primary schools and 398,361in secondary schools.

India's progressive legislation and policies form the backbone of its inclusive education framework. The Right to Education (RTE) Act of 2009 mandates access to inclusive neighbourhood schools for CwDs. The Right of Persons with Disabilities (RPwD) Act 2016 reinforces principles of non-discrimination, zero rejection, and reasonable accommodations. The National Education Policy (NEP) 2020 further builds on these foundations, aligning with SDG-4 aims to "guarantee inclusive and equitable quality education while promoting continuous educational opportunities for everyone by 2030."

Department of Empowerment of Persons with Disabilities (DEPwD) under the Ministry of Social Justice and Empowerment (MSJ&E) initiated the establishment of Cross Disability Early Intervention Centers (CDEIC) for children from birth to 6 years of age. This initiative comprehensively addresses the needs arising from various disabilities. On June 17, 2021, the DEPwD launched 14 CDEICs designed to screen and intervene for all 21 categories of disabilities recognized under the RPwD Act, 2016. These centres offer: (i) screening of children and identification of at-risk cases, (ii) therapeutic services including speech, occupational, and physiotherapy, (iii) counselling for parents and peer counselling, and (iv) preparatory school facilities to help children with disabilities become school-ready.

Inclusive classrooms in early childhood education offer substantial benefits for children with communication disorders and their peers. Rather than of segregating children for specialized instruction, special education teachers integrate their support within the classroom. This approach allows all students to learn together, with teachers receiving the necessary assistance and support (Lathan, J. 2018). Such classrooms emphasize abilities rather than disabilities, encouraging teachers to broaden their skills and connect with each student individually. Inclusive early childhood classrooms foster an environment where every pupil's needs are honoured, diverse cultures and perspectives are valued, diversity and individuality are celebrated, and shared respect and empathy are nurtured, creating a supportive and enriching learning environment for every child (ASER 2020).

Early identification and intervention for young children with disabilities yield significant long-term benefits. Evidence suggests that early intervention can have lifelong positive outcomes, helping to overcome barriers posed by disability, reduce developmental delays, facilitate learning, and alleviate family stress. These factors collectively build stronger foundations for children, enhance their educational achievements, and pave the way for inclusive education (Agrawal et al., 2023).

According to Boelter J. (2022), creating an inclusive early childhood education environment for children with communication disorders requires a multifaceted approach. Educators can support these children's unique needs by implementing various strategies, such as using universal design principles to create accessible classrooms, conducting developmental screenings, ensuring effective amplification devices, utilizing the residual hearing of a child, and adapting/accommodating/modifying infrastructure, learning material, teaching strategies and assessment. These strategies enhance learning experiences and support the diverse needs of children (NCERT, 2022). Furthermore, they emphasize the necessity of tailoring inclusive strategies to address both early developmental needs and communication barriers, especially for children with disabilities in multilingual settings (UNESCO, 2021; Sharma & Loreman, 2019).

Equipping rehabilitation professionals with the necessary skills and knowledge to support children with communication disorders is crucial. Training should focus on evidence-based strategies for enhancing communication, including using uni-sensory and multi-sensory channels, augmentative and alternative communication (AAC) tools, and Indian Sign Language. Additionally, professionals should be skilled in individualized assessment and intervention planning and techniques for fostering social interaction and language development within inclusive educational settings. This comprehensive approach ensures adequate support for the diverse communication needs of children in inclusive early childhood classrooms (Ziviani, et.al, P. 2013).

According to Nairn, J. (2023), educators should employ a variety of instructional formats, ensure semi-circle seating arrangements, and maximize the use of assistive technology. Understanding students' Individualized Education Programs (IEPs), developing behaviour management plans, and fostering a positive classroom climate is crucial. Differentiated instruction and learning styles, adaptation of teaching materials and resources, and the promoting of collaborative learning play significant roles (Yadav, S. & Upadhyay, A.2023). Furthermore, encouraging positive relationships and peer interaction, collaborating with a multidisciplinary team to provide comprehensive support, and engaging in continuous reflection and professional development are essential (Singh, K. 2023). These strategies empower educators to establish a learning environment that is inclusive, supportive, and effective for children with communication disorders, fostering academic and social success (Saikia, H. 2023).

Inclusive early childhood education in India faces several challenges, including a lack of trained educators, insufficient resources, cultural stigmas, and inadequate infrastructure (Singh. C, Pandey. Y, & Kushwaha. A., 2021). Many educators are not adequately prepared to address the diverse needs of children with communication disorders, and schools often need more materials and support systems (MoWCD, 2018). To overcome these challenges, several strategies are suggested: implementing comprehensive training programs for teachers and support staff, increasing funding and resources, conducting awareness campaigns to reduce cultural stigmas, developing and enforcing policies that mandate inclusive practices, and improving school infrastructure to accommodate the needs of all students. Additionally, fostering partnerships between parents, schools, non-governmental organizations, and government bodies help them share resources, expertise, and support systems (Kulkarni, K.A. & Gathoo; V. S., 2019).

Rehabilitation professionals are experts in helping individuals overcome physical, sensory, cognitive, or emotional disabilities. According to Section 13 of the RCI Act, 1992, only those registered with the Rehabilitation Council of India (RCI) are authorized to practice in India. As of December 31, 2022, the RCI has registered 8,952 professionals and 15,436 personnel in the Central Rehabilitation Register, reaching 194,031 registered rehabilitation professionals (DEPwD, 2023). This study highlights the critical importance of early childhood development and the challenges children with communication disorders face in accessing equitable education. Given that over 85% of brain development occurs by age six, early intervention and appropriate support are crucial (NCFFS 2022). The study aims to identify effective strategies for fostering inclusive education, emphasizing the necessity of professional training, multidisciplinary collaboration, and adequate resource allocation. Henceforth, the existing study was undertaken to study the strategies for fostering inclusive early childhood education for children with communication disorders.

OBJECTIVES:

i. To study the early intervention strategies for communication disorders.

ii. To equip rehab professionals with the necessary skills and knowledge to address communication disorders.

iii. To study inclusive teaching practices and communication-focused pedagogies.

iv. To examine the role of multidisciplinary teams in supporting inclusive education.

v. To study the challenges in inclusive early childhood education.

vi. To study and compare the impact of the field expertise of rehab professionals on their strategies for fostering inclusive early childhood education for children with communication disorders.

RESEARCH QUESTIONS:

i. What are the most influential early intervention strategies for addressing children with communication disorders?

ii. What are the most effective approaches for providing the necessary skills and knowledge needed to address communication disorders?

iii. What are the effective inclusive teaching practices and communication-focused pedagogies that enhance student engagement and learning outcomes?

iv. What is the role of multidisciplinary teams in supporting inclusive education?

v. What are the major challenges in inclusive early childhood education?

RESEARCH HYPOTHESIS:

The field expertise of rehab professionals has no impact on their strategies for fostering inclusive early childhood education for children with communication disorders.

METHODS

A descriptive survey method was used.

PARTICIPANTS

Snowball sampling techniques across India selected one hundred seventy-three CRR holder rehab professionals working in special education as the participants. Table 1 presents the participants' characteristics.

Table 1: Distribution of Participants by Professional Specialization

Gender	Strategies for Fostering Inclusive Early Childhood Education for Children with Communication Disorders					Total
	Hearing Impairment	Visual Impairment	Intellectual Disability	Audiologist and SLPs	Other Disability	
Female	35	04	46	08	11	104
Male	37	08	18	0	06	69
Total	72	12	64	08	17	173

TOOL:

The Inclusive Education Strategies Test (IEST) was developed to assess strategies for fostering inclusive early childhood education for children with communication disorders. The researcher developed tool assesses teachers' awareness and application of inclusive practices. Although the tool includes components of classroom adaptation, it has limited coverage of early intervention and communication-based pedagogies. The test comprised 20 equally weighted questions, evaluating the knowledge and competencies of RCI rehab professionals on topics such as early intervention, effective communication strategies, the importance of residual hearing, semi-circle seating arrangements, the role of a multidisciplinary team, etc. Closed-ended multiple-choice questions were created based on these areas. Face validity was established with the help of 10 experts in special education. Cronbach's alpha scores of 0.712 and 0.718 confirmed the tool's reliability. Sample items from the IEST are presented in Table 2.

Area	Sample Items								
Strategies for Fostering Inclusive Early Childhood Education	1	What does SLP stand for in the context of communication disorders and therapy?							
		a	Standardized Language Program	b	Speech and Learning Pathway	c	Speech and Language Pathologist	d	Social Linguistic Program
	2	Which age group typically falls under the early childhood category in educational contexts?							
		a	6-10 years	b	3-6 years	c	10-14 years	d	14-18 years
	3	Why early intervention is essential?							
		a	It saves costs	b	It prevents all disabilities	c	It improves the outcomes of the child	d	It is easier to implement in adulthood
	4	How can you utilize the residual hearing of a child with communication disorders?							
		a	Avoid speaking directly to them	b	Use lots of background noise to stimulate hearing	c	Speak clearly when giving instructions to use a hearing aid	d	Use sign language only
	5	Why is a semi-circle seating arrangement essential for children with communication disorders?							
		a	It ensures they sit alone to avoid distractions	b	It allows them to see your face and mouth clearly	c	It minimizes their interaction with peers	d	It prevents them from participating in group activities
	6	Which professional is typically involved in early intervention for communication disorders?							
		a	Pediatricians and Speech-Language Pathologists	b	Teachers and Parents	c	Social workers and neighbour	d	Parents and neighbour
	7	When intervening with children with communication disorders, who is not a multidisciplinary team member?							
		a	Special Educator	b	Speech therapist	c	Psychologist	d	None of the above
	8	What is a primary challenge in inclusive early childhood education?							

	a	Lack of funding and resources	b	An overabundance of specialized teachers	c	Strict adherence to standardized curricula	d	Limited parental involvement

Table 2: Sample Items in the 'IEST'

DATA COLLECTION

Informed consent was obtained from all participants, ensuring their voluntary involvement in the study, with confidentiality maintained throughout the process. After obtaining consent and finalizing scheduling, selected rehabilitation professionals participated in the administration of the 'IEST'. Professionals were instructed to mark the most suitable option for each item. Completed response sheets were then gathered. Each correct answer received one mark, and incorrect answers were scored zero. Quantitative data were subsequently encoded and analysed using SPSS.

DATA ANALYSIS

As a measure of frequency, percentage and mean scores were used to analyze the competencies of rehab professionals for strategies to foster inclusive early childhood education. ANOVA was used to analyze whether the field expertise of rehab professionals has any impact on their strategies for fostering inclusive early childhood education for children with communication disorders.

RESULTS

The inclusive early childhood education workforce involves special educators, speech-language pathologists, therapists, and other paraprofessionals who collaborate to support children with communication disorders. The increasing importance of early childhood education, particularly in inclusive settings, necessitates developing competencies in knowledge, attitude, and skills to adopt better inclusive teaching strategies for these children. This study investigates effective methods for fostering inclusivity and enhancing communication and learning for children with communication disorders.

(i) To study early intervention strategies for communication disorders.

To investigate strategies for fostering inclusive early childhood education for children with communication disorders, the study began by framing the research question ***"What are the most effective early intervention strategies for addressing children with communication disorders?"*** Figures 1-4 illustrate the responses quantitatively, presenting the numbers and percentages corresponding to the answers provided.

Fig 1- What does SLP stand for in the context of communication disorders and therapy?

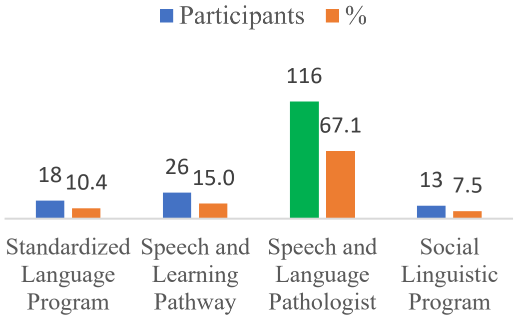


Fig 2- At what stage is it crucial to conduct developmental screenings for communication disorders?

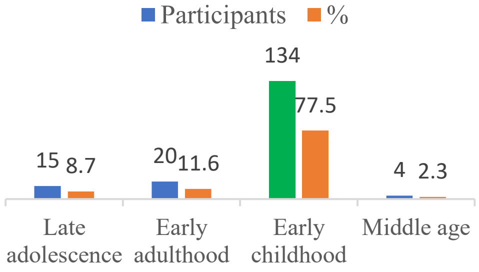


Fig 3- Which age group typically falls under the category of early childhood in educational contexts?

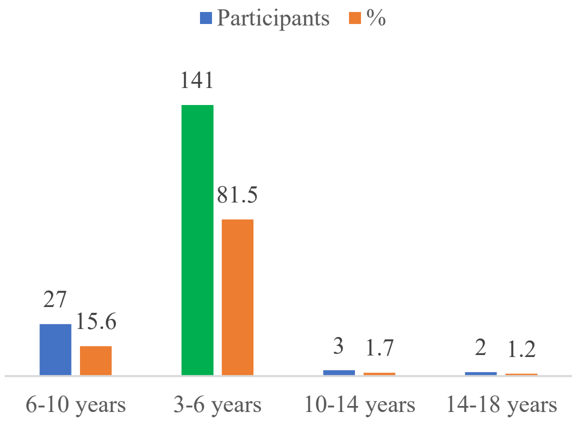
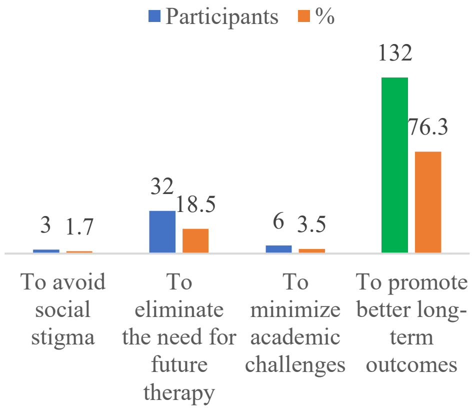


Fig 4- Why is early intervention important in addressing communication disorders?



The analysis of responses from 173 rehabilitation professionals, as shown in Figure 1 indicated that 116 professionals (67.1%) correctly identified speech and language pathologists as critical professionals for addressing communication disorders. Figure 2 shows that 134 professionals (77.5%) correctly selected early childhood as a critical period for intervention. In Figure 3, 141 professionals (81.5%) recognized the age range of 3-6 years as crucial for intervention, while Figure 4 revealed that 132 professionals (76.3%) acknowledged that early intervention promotes better long-term outcomes.

(ii) To equip rehab professionals with the necessary skills and knowledge to address communication disorders.

To explore this objective, the study began by framing the research question ***"What are the most effective approaches for providing the necessary skills and knowledge to address communication disorders?"*** Figures 5-8 quantitatively depict the responses, showing the numbers and percentages corresponding to each answer provided.

Fig 5- Why early intervention is essential?

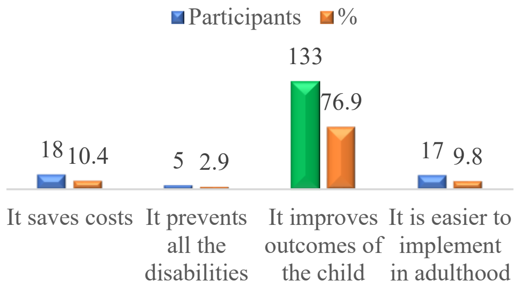


Fig 6- What does IEP stand for in education?

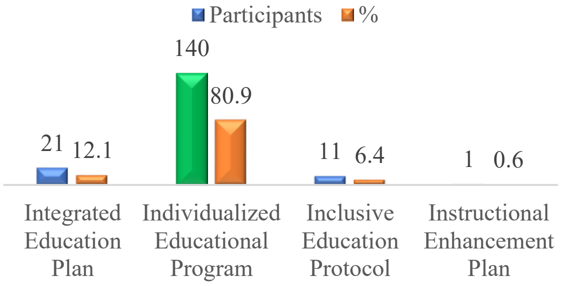


Fig 7- Which strategies ensures effective communication for children with amplification devices?

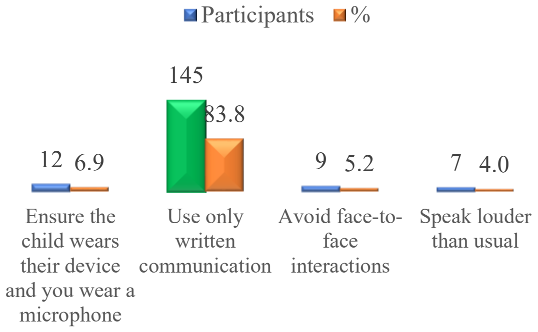
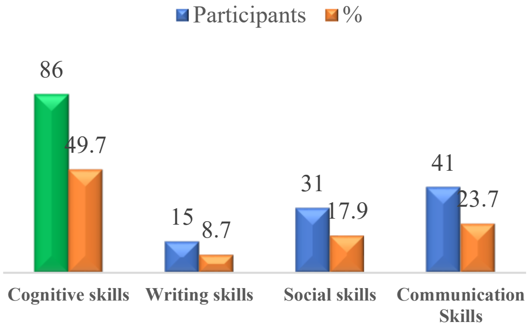


Fig 8- Children who are developmentally delayed are slower at acquiring



The analysis of responses from 173 rehabilitation professionals showed significant findings: 76.9% correctly identified that early intervention improves child outcomes (Figure 5), 80.9% recognized the Individualized Educational Program (IEP) as crucial (Figure 6), and 83.8% acknowledged written communication as an effective strategy (Figure 7). However, only 49.7% recognized slower cognitive skill acquisition in developmentally delayed children (Figure 8).

(iii) To study inclusive teaching practices and communication-focused pedagogies.

To investigate strategies for fostering inclusive early childhood education for children with communication disorders, the study began by framing the research question ***"What are the effective inclusive teaching practices and communication-focused pedagogies that enhance student engagement and learning outcomes?"*** Figures 9-12 illustrate the responses quantitatively, presenting the numbers and percentages corresponding to the provided answers.

Fig 9- How can you utilize the residual hearing of a child with communication disorders?

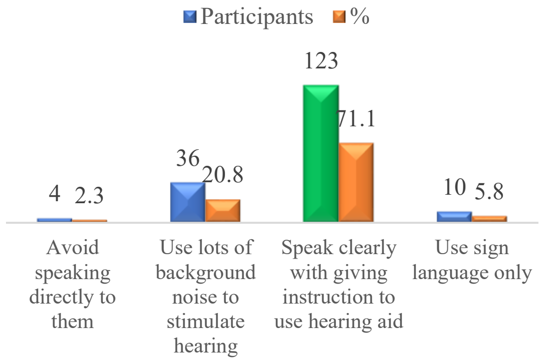


Fig 10- Why semi-circle seating arrangement is important for children with communication disorders?

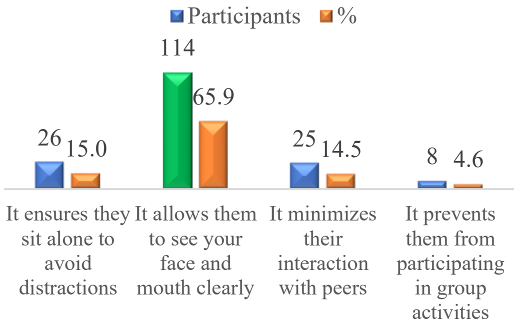


Fig 11- What is a crucial step in identifying communication disorders in children?

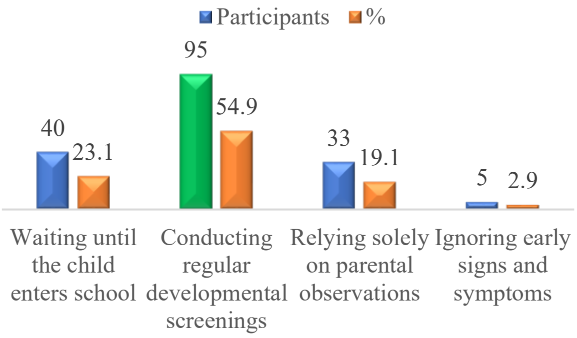
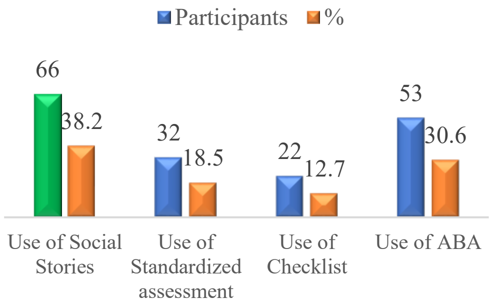


Fig 12- A technique that appears helpful in developing autistic children's awareness of normal codes of behavior



The analysis of responses from 173 rehabilitation professionals revealed significant findings: 71.1% correctly identified the use of residual hearing and hearing aids as important for clear communication during instruction (Figure 9), 65.9% recognized the benefits of a semi-circle seating arrangement for improving the visibility of facial expressions and mouth movements (Figure 10), and 54.9% acknowledged the importance of regular developmental screening in detecting communication disorders (Figure 11). However, only 38.2% recognized the efficacy of using social stories to promote the development of appropriate behaviour norms (Figure 12).

These results suggest that while many professionals grasp the significance of timely intervention and clear communication strategies, there is a need to enhance awareness regarding using social stories for behavioural development in children with communication disorders.

(iv) To examine the role of multidisciplinary teams in supporting inclusive education.

The study focused on fostering inclusive early childhood education for children with communication disorders; the study began by framing the research question ***"What is the role of multidisciplinary teams in supporting inclusive education?"*** Figures 13-16 present quantitative data showing numerical responses and corresponding percentages to address this question.

Fig 13- The __ provides insight into how emotional issues might be affecting academic performance

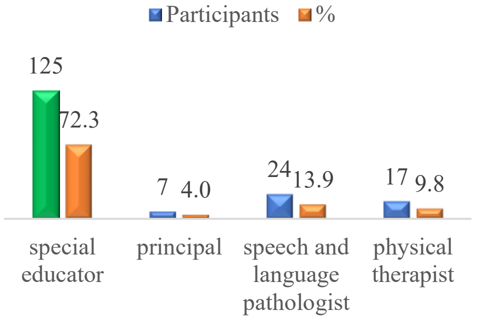


Fig 14- Which professional is typically involved in early intervention for communication disorders?

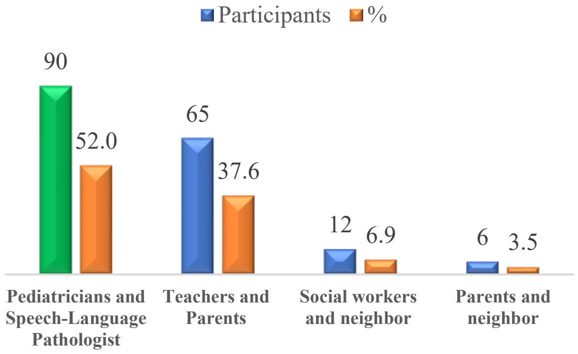


Fig 15- Who is not the member of multidisciplinary team in intervening children with communication disorder?

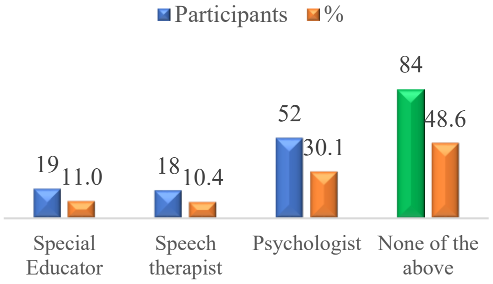
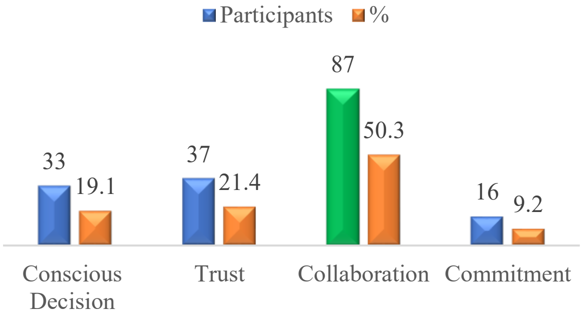


Fig 16- What characteristic of an effective team is used to resolve differences?



The analysis of responses from 173 rehabilitation professionals showed that 72.3% correctly identified special educators as pivotal in early intervention (Figure 13). Additionally, 52% recognized the roles of paediatricians and speech-language pathologists (Figure 14), while 48.6% acknowledged none of the above as the correct answer (Figure 15). Furthermore, 50.3% identified collaboration as a critical characteristic of effective multidisciplinary teams (Figure 16).

(v) To study the challenges in inclusive early childhood education.

To investigate strategies for fostering inclusive early childhood education for children with communication disorders, the study began by framing the research question ***"To what extent are the challenges in inclusive early childhood education?"*** Figures 17-20 illustrate the responses quantitatively, presenting the numbers and percentages corresponding to the provided answers.

Fig 17- What is a primary challenge in inclusive early childhood education?

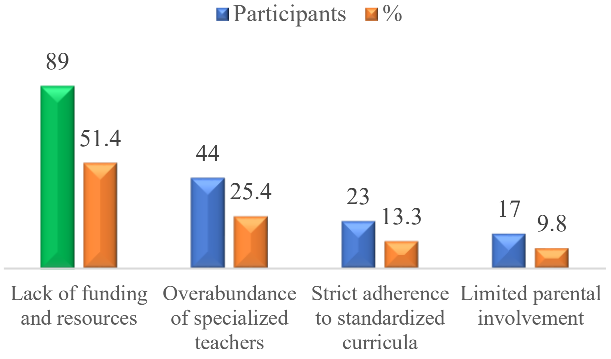


Fig 18- Difficulties in learning arise from

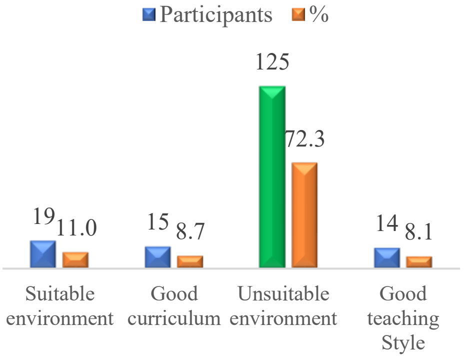


Fig 19- Why is teacher training crucial in inclusive early childhood education?

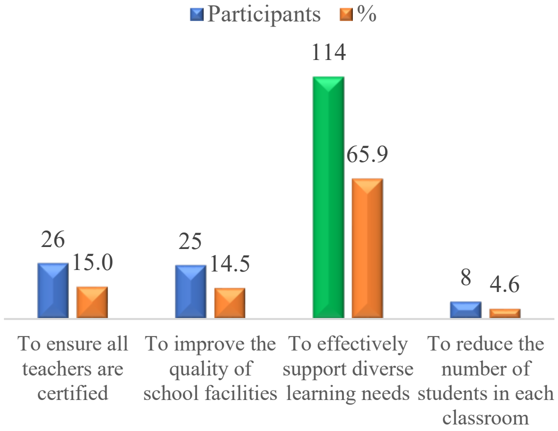
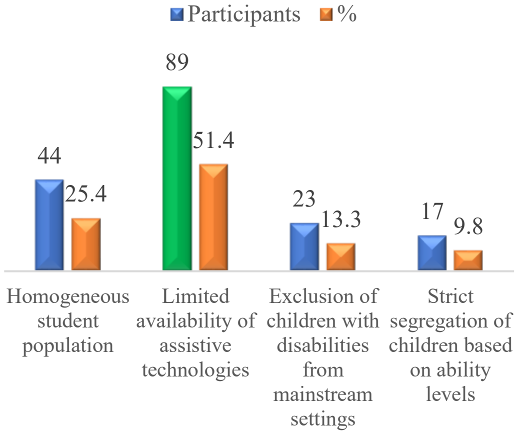


Fig 20 - Which factor contributes to the complexity of implementing inclusive education?



The analysis of responses from 173 rehabilitation professionals revealed significant insights. Specifically, 51.4% identified a lack of funding and resources as a primary challenge in early childhood education (Figure 17). Moreover, 72.3% recognized that an unsuitable environment poses difficulties in learning (Figure 18), and 65.9% emphasized the critical need for teacher training to effectively support diverse learning needs (Figure 19). Additionally, 51.4% highlighted the limited availability of assistive technology (Figure 20).

These findings indicate that while many professionals are aware of the challenges in inclusive early childhood education, there is a clear need to raise awareness and develop strategies to overcome these challenges for the improved education of children with communication disorders.

(vi) Impact of field expertise on their strategies for fostering IECE

The study further investigated the impact 'rehab professionals' field expertise on their strategies for fostering inclusive early childhood education for children with communication disorders. The null hypothesis framed at the beginning of the study was that ***"The field expertise of rehab professionals has no impact on their strategies for fostering inclusive early childhood education for children with communication disorders".*** Data were collected using a Google Form questionnaire, and a one-way ANOVA was conducted to analyse the relationship between the independent variable, field expertise, and the dependent variable, strategies for fostering IECE. For this purpose, the independent variable was categorized into five categories: (i) those having expertise in the field of hearing impairment, (ii) those having expertise in the field of visual impairment, (iii) those having expertise in the field of intellectual disabilities, (iv) those having expertise in field of audiology/ Speech Language Pathologist (SLP) and (v) those having expertise in field of other disabilities. The ANOVA table breaks down the data's variance into two components: a) the between-group component and b) the within-group component. The results obtained are mentioned below in Table 3.

Table 3: ANOVA - Expertise Vs strategies for fostering IECE

ANOVA						
	Source of variation	Sum of Squares	Df	Mean of Square	F (observed)	p
Strategies for fostering inclusive early childhood education for children with communication disorders	Between Groups	116.61	4	29.15	2.43129	0.049544
	Within Groups	2014.34	168	11.99		
	Total	2130.95	172			

The ANOVA analysis presented in Table 3 shows (F=2.431, p=0.049<0.05 at df (4, 168). The p-value of 0.049 is less than 0.05, which indicates a statistically significant difference between the means of various groups at the 5% significance level. Thus, the result was that " ***rehab professionals' field expertise has a significant impact on their strategies for fostering inclusive early childhood education for children with communication disorders."***

DISCUSSION

The findings underscore the strengths and gaps in the approaches of rehabilitation professionals toward supporting children with communication disorders in inclusive early childhood education. Most professionals exhibit a strong understanding of the importance of early intervention and possess the necessary knowledge to effectively assist these children. However, the results also highlight areas for growth, particularly in recognizing cognitive delays and adapting strategies to meet these needs.

Although many professionals understand the significance of timely intervention and effective communication strategies, there is a noticeable need to enhance their awareness of using tools like social stories to foster behavioral development. Furthermore, while a majority have a moderate understanding of the role of multidisciplinary teams, only a minority demonstrate a robust comprehension of their potential in supporting inclusive practices for children with communication disorders.

The challenges associated with inclusive early childhood education remain a barrier for many professionals, pointing to the need for increased awareness and effective strategies to address these issues. The observed variations in strategies emphasize the impact on educational outcomes for children, reinforcing the necessity for systematic in-service training as a critical policy intervention. Notably, professionals with prior inclusive training exhibit greater proficiency in adapting teaching methods, illustrating the benefits of targeted professional development. Additionally, the lower scores in communication-specific strategies across groups highlight significant gaps in both pre-service and in-service curricula. Addressing these gaps is essential for equipping professionals with the tools needed to support inclusive education effectively and improve outcomes for children with communication disorders.

CONCLUSIONS

The findings highlights the crucial role of early intervention, comprehensive professional training, and effective inclusive teaching practices in supporting children with communication disorders. The data demonstrate that most rehabilitation professionals understand early intervention and the competencies required to address communication disorders. However, there is a need for enhanced awareness of specific strategies, such as using social stories and recognizing cognitive delays. Additionally, the significant impact of multidisciplinary collaboration and field expertise on fostering inclusive education underscores the importance of targeted professional development and resource allocation. The study's datasets, generated and analyzed, can be obtained upon reasonable request from the corresponding author, ensuring access for further research while maintaining ethical and confidentiality standards.

EDUCATIONAL IMPLICATIONS:

The study underscores the necessity of continuous professional development for educators and therapists to make sure they are well equipped with the latest knowledge and skills to support children with communication disorders. It also highlights the need for increased funding and resources to address the challenges identified, such as inadequate assistive technology and insufficient training opportunities. By prioritizing these areas, educational institutions can create more inclusive environments that promote better long-term outcomes for children with communication disorders, ultimately enhancing their learning experiences and social integration.

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Review Article

Towards Comprehensive Cardiovascular Care: The Part of Community-Based Rehabilitation in Controlling Cardiovascular Risk Factors in Indonesia

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ABSTRACT

Aim: Alternative models of cardiac rehabilitation (CR) have emerged globally to address the underutilization of hospital-based programs. Community-based cardiac rehabilitation emphasizes patient assessment, risk stratification, education, counseling, and program evaluation. This review aims to understand the forms of community-based rehabilitation that can be implemented to enhance cardiovascular health and specifically explores their roles and applications in Indonesia.

Methods: A comprehensive literature search was conducted in PubMed and Google Scholar using the keywords “cardiac rehabilitation”, “community-based cardiac rehabilitation”, and “cardiac rehabilitation in Indonesia”. We also identified relevant guidelines and textbook resources. The search was limited to articles written in English and Indonesian, and published over the past twenty years.

Results: Out of 644 retrieved articles, only 50 met the inclusion criteria and were used for the review.

Conclusion: Community-based CR is effective for patients with heart failure and acute coronary syndrome post-intervention. In Indonesia, initiatives like the chronic disease management program or *program pengendalian penyakit kronis (P*rolanis) and the integrated non-communicable disease service post or *pos pembinaan terpadu penyakit tidak menular* (Posbindu PTM) target hypertension and diabetes, key risk factors for cardiovascular diseases. However, significant disparities in awareness and treatment persist, highlighting the need for robust strategies to enhance prevention and control within community-based CR frameworks. This narrative review underscores the potential of community-based approaches to improve cardiovascular health outcomes in Indonesia and beyond.

Keywords: Cardiovascular health, community-based cardiac rehabilitation, developing country, risk factor control

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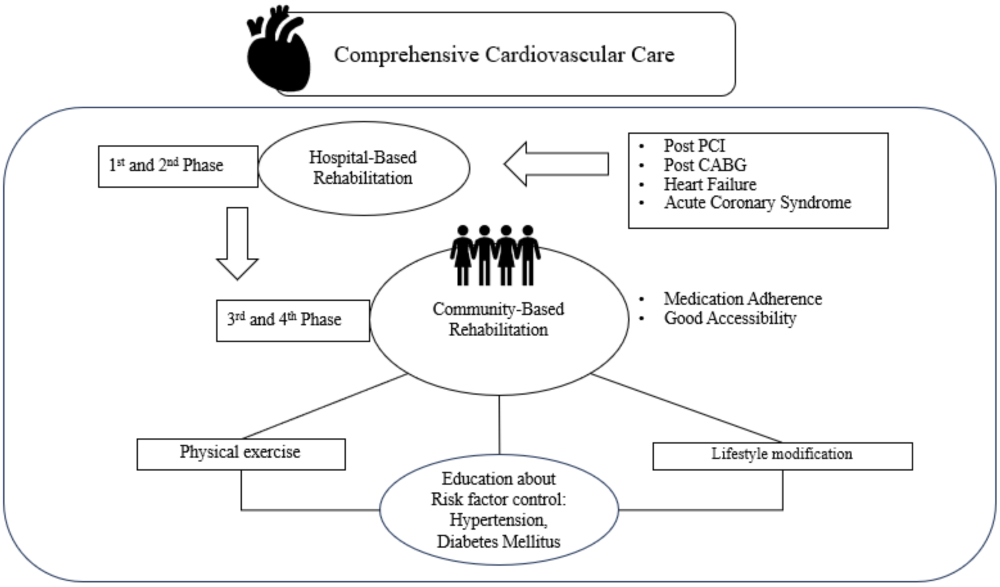
INTRODUCTION

Since 1994, the American Heart Association (AHA) has advocated for a comprehensive approach to cardiac rehabilitation, extending beyond physical exercise programs, to address modifiable risk factors (Ardiana, 2022b). Participation in a cardiac rehabilitation program has been linked to a 26% decrease in cardiovascular disease mortality and an 18% reduction in re-hospitalization rates (Anderson et al., 2016). However, conventional hospital-based programs face under-utilization due to barriers such as geographical access, time constraints, and family obligations. To address this, alternative models like home- or community-based programs have been developed globally. Out of 111 countries with cardiac rehabilitation programs, 76.6% offer supervised programs, and 45.9% provide alternative programs, including home-based (38 countries) and community-based (25 countries) approaches (Lima de Melo Ghisi et al., 2018). Community rehabilitation, conducted in the 3rd and 4th phases of cardiac rehabilitation, involves remote monitoring via technology and supervised visits by healthcare professionals, comprising patient assessment, risk stratification, education, counseling, and program evaluation. The 3rd phase focuses on exercise programs and formal education over 3–6 months, while the 4th phase efforts can extend beyond hospitals through non-governmental organizations or community groups (B. Radi, 2009). Community-based cardiac rehabilitation has demonstrated effectiveness in improving outcomes for patients with various cardiovascular conditions, including those who have undergone percutaneous coronary intervention (PCI), coronary artery bypass grafting (CABG), heart failure, and patients recovering from acute coronary syndrome (ACS) (Tucker et al., 2016; Xiao, Li, & Guan, 2021; Zhang et al., 2024).

In Indonesia, the Ministry of Health supports rehabilitation services in both hospitals and communities, such as the integrated non-communicable disease service post or pos pembinaan terpadu penyakit tidak menular (Posbindu PTM) and chronic disease management program or program pengendalian penyakit kronis (Prolanis), which aim to control risk factors for non-communicable diseases, including cardiovascular disease. They are aimed to be part of community-based rehabilitation against cardiovascular disease, although their implementations remain challenging. Low participation rates stem from a lack of awareness and understanding of the benefits these programs offer (Ariana, Sari, & Kurniawan, 2020; Fadila & Ahmad, 2021). Additionally, barriers to adherence, such as cultural dietary habits and reliance on traditional medicine, further complicate engagement (Aungsuroch, Gunawan, Polsook, & Anuruan, 2021). Health system limitations, including inadequate resources and personnel, also hinder effective program delivery (Putri, Mawarni, Trisnantoro, & Health, 2020). Furthermore, communication and educational gaps surrounding the importance of these rehabilitation services contribute to the difficulties in running Prolanis and Posbindu PTM effectively (Ariana et al., 2020; Fadila & Ahmad, 2021). Addressing these challenges requires a concerted effort to enhance public awareness, improve healthcare infrastructure, and foster a supportive environment that encourages participation in community-based cardiac rehabilitation initiatives. In light of these needs, this review aims to provide a comprehensive understanding of community-based cardiac rehabilitation and its role in the management of cardiovascular health. The study delves into the definition, purpose, benefits, exercise options, encountered barriers, and implementation of community-based cardiac rehabilitation in the global and Indonesian context. By exploring these elements, the review seeks to identify effective strategies for overcoming existing challenges and promoting better cardiovascular health outcomes.

TABLES AND FIGURES



METHODS

A comprehensive literature search was conducted in PubMed and Google Scholar using the keywords "cardiac rehabilitation", "community-based cardiac rehabilitation", and "cardiac rehabilitation in Indonesia". The inclusion criteria for this study were any research method (review, experimental studies, and observational studies), limited to articles written in English and Indonesian, and published over the past twenty years. We also identified relevant literature, such as study protocols, reviews, policy papers, report, book chapters, and non-peer-reviewed documents.

RESULTS

Out of 644 retrieved articles, only 50 met the inclusion criteria and were used for the review. An integrative review was conducted in reviewing all evidence related to the community-based cardiac rehabilitation, with a focus on its application in Indonesia. The collected data is subsequently organized based on the relevant topics and discussions of the identified issues. This includes a global overview of community-based cardiac rehabilitation, its application to specific cardiovascular diseases, and an analysis of its implementation in Indonesia, with particular attention to its potential for further development.

DISCUSSION

Cardiac rehabilitation, centered on physical exercise, aims to enhance or maintain various aspects of physical fitness. Individuals, including those with cardiovascular disease, are encouraged to engage in increased physical or aerobic exercise to improve their cardio-respiratory fitness (Ardiana, 2022b). The measurement of physical exercise in cardiac rehabilitation encompasses cardio-respiratory fitness, strength, and muscle flexibility (Medicine, 2018). Specifically, aerobic exercises, characterized by rhythmic movements involving large muscle groups, yield positive effects on the heart, blood vessels, muscle fitness, and strength (Ardiana, 2022b).

Cardiac Rehabilitation Phase

The comprehensive approach to cardiac rehabilitation aims to optimize cardiovascular health through targeted physical exercise interventions. Cardiac rehabilitation initiates once the patient's hemodynamics stabilize and there have been no occurrences of chest pain or changes in electrocardiography (EKG) pattern for the preceding 8 hours. The rehabilitation process, organized based on time and purpose, comprises four distinct phases: the first phase (inpatient rehabilitation), the second phase (outpatient rehabilitation), the third phase (maintenance program), and the fourth phase (lifelong maintenance) (Ardiana, 2022a). While some literatures outline a three-phase division of cardiac rehabilitation, this review specifically focuses on the four-phase model (Makita et al., 2022). The third phase, or maintaining phase, aims to maintain the achieved conditions in first and second phase, prevent recurrent attacks, promote disease stability, and facilitate a return to work (Makita et al., 2022; Trust, 2011). The fourth phase constitutes a lifelong maintenance phase with overall monitoring by the primary healthcare team on a weekly basis. In this phase, patients can engage in independent exercises at home or join healthy heart clubs. The exercise program is tailored to individual capabilities, and cessation is advised if patients experience chest pain, shortness of breath, nausea, vomiting, severe arrhythmia, cold sweats, or excessive fatigue (Trust, 2011).

Community-based Cardiac Rehabilitation: Participation and Implementation

Cardiac Rehabilitation: Home-Based and Community-Based Approaches

Cardiac rehabilitation has proven health benefits and is recommended for patients with cardiovascular diseases. However, patients often face multilevel barriers, such as accessibility, geographical location, and distance to hospitals, when participating in hospital-based cardiac rehabilitation programs. To address these challenges, alternative forms of cardiac rehabilitation programs have been developed, including home-based cardiac rehabilitation (HBCR) and community-based cardiac rehabilitation (CBCR) (Nagatomi et al., 2022).

In home-based rehabilitation, patients undergo an initial assessment at a cardiac rehabilitation center, where their safety for independent exercise is evaluated and a tailored exercise prescription is developed. Exercises are performed without formal supervision, and regular contact through phone or other technologies is established to review the exercises. In community-based rehabilitation, local exercise facilities are utilized, and cardiac rehabilitation staff visit these centers to provide comprehensive services. Alternative models consist of home-based rehabilitation (utilizing information and communication technologies), community-based programs, and hybrid programs (Lima de Melo Ghisi et al., 2018).

The overarching goal of community-based rehabilitation programs is to promote and support long-term adherence to exercise and healthy lifestyle behaviors. Maintenance is structured, with exercise programs tailored to individual conditions and accessibility needs, covering cardiac, behavioral, and psychological aspects (S. Mandic, 2018). Continuation programs, or the third phase of cardiac rehabilitation, can take various forms, ranging from services similar to hospital-based outpatient clinics to clubs or associations managed and run by patients themselves. These programs go beyond providing physical exercise; they also offer health education on nutrition and psychological counseling. Their vital role in the recovery and maintenance of functional capacity and psychological health for patients with cardiovascular diseases is significant. Success is achieved when these programs are grounded in strong scientific principles while maintaining sensitivity to the social and cultural context of individuals and communities (S. Mandic, 2018).

Cardiac Rehabilitation: Community-Based Approach and Maintenance Phase

To date, there is no universal agreement on the definition of community-based cardiac rehabilitation. However, in their implementation, guidelines for community-based cardiac rehabilitation typically incorporate the core components of cardiac rehabilitation, which include structured exercise, patient education, and counseling. Programs are implemented in shared facilities, with the cardiac rehabilitation team visiting these facilities to deliver comprehensive services (Lima de Melo Ghisi et al., 2018).

In the maintenance phase, the emphasis of exercise programs is on aerobic exercises. For patients with a functional capacity above 5 METs, exercise programs are designed based on heart rate and Rating of Perceived Exertion (RPE). The recommended exercise frequency is 3–4 times a week, starting with a duration of 10 minutes and gradually increasing to 60 minutes. Various methods can be employed, including interval training, circuit training, circuit-interval training, and continuous training (Arovah, 2010).

Community-based Cardiac Rehabilitation in Disease Groups

Post-PCI Cardiac Rehabilitation: Community-Based Approach

Post-percutaneous coronary intervention (PCI) cardiac rehabilitation has been proven instrumental in reducing mortality rates, alleviating patient symptoms, enhancing functional capacity, improving Quality of Life (QoL), promoting early return to work, and enhancing self control among patients (Xiao et al., 2021). According to a meta-analysis conducted by Yang et al. (2017), cardiac rehabilitation has been shown to reduce angina recurrence, improve ST-segment patterns, as well as increase total exercise time and maximum exercise tolerance in post-PCI patients. In a study by Xiao et al. (2021), community-based cardiac rehabilitation in post-PCI acute myocardial infarction patients was found to reduce the risk of major adverse cardiac events (MACE), improve heart function, and enhance physical stamina. However, most hospital-based cardiac rehabilitation programs face time limitations with short-duration programs (less than 3 months). Hence, community-based rehabilitation becomes crucial in sustaining the benefits acquired from prior hospital rehabilitation.

Post-Coronary Artery Bypass Graft (CABG) Rehabilitation

The target parameters for post-CABG patients who have completed phase II rehabilitation are evaluated based on several components: 1. Functional Capacity: Recommended to achieve 5–6 METs. 2. Health Status: a) Normal hemodynamic response during exercise (normal blood pressure, EKG, no arrhythmia); b) Absence of angina or stable angina pectoris; c) Resting heart rate <90 beats per minute; stable and controlled blood pressure at rest (<140/90 mmHg); 3. Relevant Physical Activity: Relevant to daily activities, working with a capacity of 5–6 METs. 4. Education: Patients should be able to comprehend: a) The definition of cardiovascular disease; b) Cardiac rehabilitation program; c) Healthy lifestyle for coronary heart disease risk factor modification; d) Reasons for therapy; e) Activity limitations, including sexual, vocational, and recreational activities; f) Personalized exercise based on prescription and recognizing warning signs; g) Signs and symptoms of exercise intolerance due to fatigue. Patients meeting these parameters enter phases III–IV of 3-6 months cardiac rehabilitation, with a target functional capacity of 6–8 METs (Ong et al., 2016). The American Association of Cardiovascular and Pulmonary Rehabilitation (AACVPR) and the American College of Sports Medicine (ACSM) recommend community-based programs only for low-risk patients, providing both aerobic and resistance exercises (Arovah, 2010).

Heart Failure Rehabilitation

Heart failure results in persistent morbidity and mortality, despite significant improvements in treatment (Ponikowski et al., 2016). Exercise intolerance is one contributing factor to the decreased quality of life in heart failure patients, marked by fatigue and dyspnea even with low workloads. The degree of exercise limitations is not only associated with the level of heart dysfunction but involves non-cardiac factors such as peripheral disorders (vasoreactivity, disorder of the skeletal muscle energy metabolism, and functional iron deficiency) (Conraads et al., 2013). Exercise in heart failure patients has been proven to increase peak oxygen consumption (peak VO2), with minor changes in peak VO2 are associated with significant improvements in patient outcomes (Xiao et al., 2021).

Exercise is expected to improve both central and peripheral disturbances and is clinically linked to increased quality of life, exercise capacity, and clinical improvement in patients with heart failure (Tucker et al., 2016). Exercise in patients with heart failure is recommended based on an individualized approach. Training protocols vary in method (continuous and interval), intensity (aerobic and anaerobic), and type (endurance and resistance). Continuous endurance exercise is considered the most effective and safe form of exercise, marked by steady-state aerobic conditions with moderate-to-high exercise intensity, allowing patients to engage in long exercise sessions (45–60 minutes) using a bike or treadmill (Stoylen et al., 2012). After completing exercise in a structured and supervised centralized program for 8–12 weeks, a gradual shift to a home-based program can stimulate patients to adhere to exercise and remain active for a longer period (Ardiana, 2022a). To enhance long-term exercise compliance, patient preferences for specific types of exercise should be considered. During this period, self-care management plays a crucial role in successfully achieving improvements in symptoms of heart failure, functional capacity, morbidity, prognosis, and quality of life (Ardiana, 2022b). Self-care management aims to maintain physical stability, avoid behaviors that worsen conditions, and detect early signs of worsening heart failure, including medication adherence, weight monitoring, physical exercise, and fluid intake (PERKI, 2015; Johansson, van der Wal, Stromberg, Waldreus, & Jaarsma, 2016).

High-intensity exercise is not recommended for heart failure patients. Exercise can start with low intensity, around 30% of maximum muscle strength (Piepoli et al., 2011). Studies have reported that low-intensity exercise can be balanced by increasing exercise frequency (Csapo & Alegre, 2016).

Rehabilitation after Acute Coronary Syndrome

A randomized clinical trial conducted by Bertelsen et al. (2013) aimed to explore the accessibility and benefits of community-based cardiac rehabilitation for patients with acute coronary syndrome. The study concluded that patient participation in post-hospitalization advanced rehabilitation programs is strongly influenced by social factors, with the patient's family playing a significant role. The long-term advantages of cardiac rehabilitation programs participation were highlighted in an Australian study with a 14-year follow-up of 281 patients. Patients with less than 25% participation had twice the mortality rate compared to those participating in more than 75% of the program (Beauchamp et al., 2013).

Evaluation and Monitoring in Community-based Cardiac Rehabilitation

Numerous studies have been conducted to assess the benefits of cardiac rehabilitation, focusing on outcomes related to quality of life, reduced mortality, and hospital admissions (Dalal, Doherty, & Taylor, 2015; Goel, Lennon, Tilbury, Squires, & Thomas, 2011). Additionally, clinical parameters such as blood pressure, total cholesterol (TC), low-density lipoprotein cholesterol (LDL), and triglycerides (TG) have also been employed (Dalal et al., 2015; Kubilius et al., 2012; Richardson et al., 2008). Ong et al. (2016) conducted a cohort study to evaluate outcomes following a community-based cardiac rehabilitation program. At the 1-year follow-up, the evaluation revealed statistically significant improvements, including improvement in all lipid profile parameters, fasting blood sugar levels, systolic and diastolic blood pressure, increase in 6MWD, and maximum heart rate during 6MWT.

Understanding community-based cardiac rehabilitation as an integral component of comprehensive cardiovascular care, it is essential to develop and implement strategies that incorporate the core component of cardiac rehabilitation. These strategies should be tailored to the specific needs and context of the Indonesian population, ensuring that they complement existing cardiovascular care efforts and enhance patient outcomes through multidisciplinary and comprehensive approaches.

Development of Community-based Cardiac Rehabilitation in Indonesia

While the theoretical framework of community-based cardiac rehabilitation emphasizes a multifaceted approach encompassing exercise programs, lifestyle modifications, psychosocial support, and long-term follow-up, the practical implementation in Indonesia takes on a different form, while still aligning with the core principles of the ideal framework. This is crucial in addressing the growing burden of cardiovascular disease in Indonesia, which can be effectively tackled through community-based interventions that prioritize risk factor screening, precise risk stratification, and aggressive guideline-directed treatment (Waranugraha, 2022). Various stakeholders within the community structure play a pivotal role in the implementation of community-based rehabilitation. This includes policymakers who serve as decision-makers, health professionals who lead clinical interventions, and community leaders who collaborate with specially trained cadres. These cadres, often consisting of trained volunteers or community health workers, are responsible for executing preventive rehabilitation initiatives at the local level, ensuring that services are accessible to the needs of the community.

Recent studies have demonstrated the efficacy of community-based cardiac rehabilitation in Indonesia, highlighting its benefits in medication adherence, improving quality of life, and reducing rehospitalization rates among patients with stable coronary artery disease (Karimullah, Rohman, Adriyanto, Tjahjono, & Widito, 2020). Community-based programs typically include educational sessions on disease management, medication adherence, and understanding of drug side effects. By enhancing individuals' understanding and confidence in managing their conditions, these programs improve health literacy, which is directly correlated with more optimal disease management, greater self-care involvement, and better clinical outcomes (Tan, Cheng, & Siah, 2019). Additionally, cardiac rehabilitation also significantly enhances health behaviors among participants, encouraging them to adopt healthier lifestyle choices that are crucial for effective cardiac rehabilitation (Herliani, Matchim, & Kritpracha, 2016). Community-based programs have been shown to decrease systolic and diastolic blood pressure, as well as fasting blood glucose levels, which are critical in managing cardiovascular risk factors (Soltani et al., 2021). Furthermore, community-based interventions have demonstrated improvements in blood glucose levels and physical fitness, such as increased 6-minute walk distance, which are essential for successful rehabilitation (Baek et al., 2020). The services are often integrated within primary healthcare settings, which may not fully align with the specialized focus on ideal cardiac rehabilitation but it can enhance accessibility (Nugraha et al., 2021). Indonesia's community-based cardiac rehabilitation initiatives can play a pivotal role in managing cardiovascular risk factors, particularly in integrating post-cardiac event rehabilitation and long-term cardiac care. The role of community-based cardiac rehabilitation in Indonesia is schematically summarized in figure 1.

In 2015, hypertension was the primary risk factor for cardiovascular disease and accounted for 41% of all disability-adjusted life-years lost (Disease, Injury, & Prevalence, 2017). The prevalence of hypertension in Indonesia in 2014, adjusted for age, stood at 30.2% (Sujarwoto & Maharani, 2020). The persistence of hypertension is notable in low- and middle-income countries (LMICs). Analysis also indicates that 41.8% of those with hypertension were aware of their condition, with a higher percentage observed in urban settings (42.4%) compared to rural areas (41.4%). Treatment for hypertension was received by only 5.9% of individuals residing in rural areas, a slightly higher proportion than the 7.3% observed in urban areas. These findings highlight the enduring disparities in hypertension care between urban and rural areas, despite governmental initiatives aimed at improving healthcare accessibility, such as universal health coverage in early 2014, through Jaminan Kesehatan Nasional (JKN) (Sujarwoto & Maharani, 2020).

The Indonesian government launched Prolanis (Program Pengendalian Penyakit Kronis) in 2010 with the goal of managing chronic diseases, specifically diabetes and hypertension. Following the introduction of universal health coverage (UHC) in 2014, the program is still in place (Khoe, Wangge, Soewondo, Tahapary, & Widyahening, 2020). By signing up for this program, patients with chronic illnesses can get the following benefits: 1) health education and medical advice; 2) routine health status monitoring; 3) home visit; 4) SMS gateway-based smartphone reminders; 5) club activities; and 6) regular monthly medication administration (BPJS, 2012). The number of Prolanis participants increased from 11,000 in 2014 to 250,000 in 2016, with 70% of them being adults residing in Java. Among the various activities in Prolanis, physical activity recorded the highest participation (GBD, 2017). This element is recognized as one of the core components of cardiac rehabilitation. However, the current physical activity protocols necessitate adjustments to align with established recommendations for cardiac rehabilitation. Specifically, it is essential to focus on aerobic exercise with appropriate frequency, intensity, and duration to optimize its effectiveness in enhancing cardiovascular health.

In addition to the Prolanis program, the Indonesian government also implements the integrated non-communicable disease service post (Posbindu PTM) as one of the strategies to control non-communicable diseases (NCDs) such as heart disease, diabetes mellitus (DM), chronic obstructive pulmonary disease (COPD), cancer, and illness brought by violence and accidents. Targeting anybody above the age of 15, especially those of productive age, the program is a community-based initiative managed by community health cadres (volunteers) under the direction of primary healthcare center (PHC) authorities. Its goal is to empower communities to screen for non-communicable diseases (NCDs) and associated risk factors (Kemenkes, 2012; Moeloek, 2017). It also represents community participation in integrated, regular, and periodic monitoring of the primary NCD risk factors and early detection initiatives. The activities are integrated into existing community-based health efforts, either in the workplace, company clinics, educational institutions, or other places where communities gather or engage in regular activities. The activities include 10 aspects, such as blood sugar examination, total cholesterol and triglyceride assessment, counseling and education, and communal physical activity or sports, among others (BPJS, 2012).

These multi-faceted chronic disease management strategies combine pharmacological and non-pharmacological strategies (e.g., education, physical activity, reminder system, and monitoring) in their interventions. Primary healthcare facilities already run the program in association with the national health insurance agency. Primary care clinics, private offices, and community health centers (Puskesmas) comprise the primary healthcare centers (Disease et al., 2017). A study conducted by Widyaningsih et al. (2022) on primary healthcare centers (PHC) in 3 provinces and 7 districts in Indonesia found that 80% of the visitors to Posbindu for hypertension screening and risk factor assessment were women, and 50% of them were adults aged 50 years and older. Out of the 95.1% of patients who visited and had their blood pressure checked, 35.3% showed an increase in blood pressure. Additionally, less than 80% of patients underwent anthropometric measurements, less than 25% were interviewed about NCD risk factors, and less than 15% had their blood cholesterol checked. The main obstacles in implementing effective hypertension screening identified in the study included insufficient resources and time for conducting these examinations. The data also revealed that, on average, patients visited Posbindu about 12 times in 2 years (Widyaningsih et al., 2022).

A study conducted by Sujarwoto et al. (2020) provided substantial evidence regarding the positive effect of Community-Based Health Interventions (CBHI) towards healthcare and health outcomes. While earlier study has frequently emphasized the advantages of CBHIs in family planning, nutrition access, and the prevention of communicable diseases, their study clearly shows a link between increased awareness, treatment, and management of hypertension and CBHI involvement for NCDs (Ekman, 2004; Fauveau, Stewart, Khan, & Chakraborty, 1991; Yip et al., 2007). Furthermore, the study indicates that engagement in CBHIs for NCDs was associated with increased treatment and awareness among respondents who have hypertension, but not with blood pressure management. For policymakers, these findings underline the importance of implementing additional services and strategies to improve hypertension prevention and control. This could involve the introduction of health education initiatives along with other preventive approaches to managing hypertension as one of the primary risk factors for cardiovascular disease.

The implementation of community-based cardiac rehabilitation in Indonesia, while distinct in its approach, effectively aligns with the core principles of the ideal model. Through innovative strategies such as home-based rehabilitation and integration within primary healthcare, these programs enhance accessibility and empower patients to manage their health more effectively. Government initiatives like Prolanis and Posbindu PTM further support these efforts by providing comprehensive chronic disease management and promoting health education within communities. The positive outcomes observed in medication adherence, quality of life, and cardiovascular risk factor management underscore the potential of these initiatives to address the growing burden of cardiovascular diseases in Indonesia. Continued investment in community-based strategies is essential for improving health outcomes and ensuring sustainable care for patients with chronic conditions, particularly in low- and middle-income settings.

CONCLUSIONS

Community-based cardiac rehabilitation has emerged as a viable alternative to hospital-based programs, addressing challenges like accessibility and geographical constraints. Despite the recognized effectiveness of cardiac rehabilitation in reducing cardiovascular disease mortality and morbidity, patients often encounter barriers that hinder their participation in hospital-based programs. In response to this, community-based initiatives aim to enhance involvement in cardiac rehabilitation, particularly during the maintenance phase throughout individuals' lives. Promoting and maintaining long-term adherence to physical activity and good living practices is given top priority in the programs. Global findings indicate that 54.7% of all nations implement cardiac rehabilitation programs, with 76.6% incorporating supervised rehabilitation. In Indonesia, both governmental and non-governmental programs have been implemented to support community-based cardiac rehabilitation in terms of risk factor control, especially hypertension and diabetes mellitus. They are run by the community, with cadres spearheading the implementation of the program and the health workers at primary healthcare centers as supervisors. Further studies are needed to evaluate the effectiveness and development path of the program to align with the overarching goal of supporting a lasting commitment to a heart-healthy lifestyle.

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