



DISABILITY, CBR & INCLUSIVE DEVELOPMENT

Formerly Asia Pacific Disability Rehabilitation Journal

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Editorial Summer Issue 2022

Power at your Fingertips to empower Others!

In the year 1989, the renowned journal *Social Science and Medicine* published an article titled “Information-Based Rehabilitation for Third World disability” by the late Mike Miles¹. Thirty years down the line the title of this manuscript could come in for criticism, yet there is an interesting and important concept it refers to, namely the focus on information-based rehabilitation. For those familiar with the debates of that time, it is obvious that Miles was playing with the abbreviation IBR in the title of his article; the supporters of Community-Based Rehabilitation (CBR) were adamant about the limited value of institutions and thus Institution-Based Rehabilitation (IBR). They understood the serious limitations of institutions to respond adequately to the needs of large numbers of people with disabilities and the isolated work of institutions with little community-level impact. Miles was playing with words and realised – being serious about the importance of information – that there was another meaning for the abbreviation IBR: one that would prove to be even more powerful than anything else related to whatever model of rehabilitation would be offered. He realised that development can be realised when people are truly involved and informed.

Coincidentally, I bought my first computer in the same year, and increasingly came to realise that if there was one thing needed to contribute to a fundamental process of change, it was to invest in developing the capacity of people rather than in setting up structures and projects. With videos becoming more and more common – even our Primary Health Care programme in rural South Africa knew this and had access to a mobile video unit – we understood the importance and power of information probably better than large numbers of health educators who, at that time, thought a poster was sufficient to inform people and/or change their mindset. Health professionals, who continued to invest in posters which became faded and thus illegible in no time, were not even in a position to do so.

In the eighties and nineties in South Africa, we also understood that information was of vital importance in the empowerment process of communities. Information was, as an initiated process, enabling the masses to gain power and extend it in such a way as to have a share in changing social, economic and political

1 Miles, M. (1989). Information-based rehabilitation for Third World disability. *Social Science & Medicine*, 28(3), 207–210. [https://doi.org/10.1016/0277-9536\(89\)90263-3](https://doi.org/10.1016/0277-9536(89)90263-3)

structures; and in so doing, to influence their own circumstances and participate in their own development.

Now, so many years later, we have information literally at our fingertips, along with the means to contribute to the much-needed system change whereby the poor get a more equal stake in the development of their country. Information is, in my view, fundamental to a process of change, but we seem to be only at the onset of understanding and using this to a certain extent!

On several occasions, and on different platforms, I have been indicating that often people with disabilities or their families, as well as rehabilitation cadre in low-resource countries, have limited (access to) contextually appropriate knowledge and information. Apart from the serious lack of knowledge and information, the poor documentation of information about simple but essential aspects of assessments, rehabilitation or development goals, and action needed to achieve these goals as well as monitoring data, is at times astonishing. This is particularly true for rehabilitation fieldworkers as well as many professionals who do not see the need or have the means or structures in place for documentation. At best, they have a manual registry or a client-based reporting system which is limited to minimal - and hard to read - notes made during an assessment, and maybe some interventions that are stated, but there is seldom an account of progress being made. Sometimes they have to fill out almost a dozen different forms with no idea about their purpose. Often, there is no purpose other than deriving generic data for an annual report, or reporting to donors, or storing the data for future research. It is seldom that clear documentation includes information about assessment, priority setting, goals, required interventions to reach those goals, referrals, as well as monitoring information. One may imagine the nightmare that evaluators face when trying to trace important information that simply does not exist. They are often confronted with cupboards full of files that grow larger by the day, but which never have and never will be used to learn from or be acted upon.

Although an exaggeration, the description above is close to the truth. During one evaluation assignment, I had to collect client documentation from underneath the bed of the CBR worker. During yet another evaluation assignment, I noticed that the fieldworkers were using 11 different ways to document data, e.g., an A-4 size registration book, various tally sheets, specific forms for specific conditions, and a form to write down individual rehabilitation plans and report on a regular basis on the progress being made.

While in some situations it would still be appropriate to continue working with manual client information systems, the opportunities have widened with the introduction of computers. Nowadays with rapid developments in digital or mobile health (m-health) applications, rehabilitation of people with disability as well as monitoring community development programmes focusing on the development of more inclusive societies have become increasingly possible and available. As such a Smartphone can become a tool that can revolutionise self-management in people with a disability and their families, while it can also be used for monitoring individual progress of personal and meaningful goals and development in various life domains. A Smartphone can make knowledge accessible to people in the most remote places of the world and it is high time that this happens. For too long, large groups of people with and without disabilities and rehabilitation fieldworkers have been deprived of information, whether deliberately or otherwise. People who have access to information and who are thus in power –with disability or not – seem at times to keep that information to themselves. The results are evident: masses of uneducated and exploited people hear the elite talking in terms they hardly understand. There are still large groups of people who are deprived of information and have no access to essential services. Health and rehabilitation professionals are often not willing to empower them and instead use their white coat or stethoscope to reaffirm the fact that they are the ones in power; many governments are not interested in empowering citizens because they too fear to lose their power; the elite of the disability movement may talk about empowerment but are comfortable with the position they have; and I often ask myself the question, “But who then is doing this?”

The answer probably is not only “who” but also “what” is doing it. Increasingly I believe it is digital information in the field of disability and rehabilitation that can play a considerable role in informing people and informing those who work in their interest. It is high time that we give knowledge back into the hands of parents of people with disabilities and children with disabilities. This can best be done by focussing on the transfer of information, knowledge, and skills.

The recently launched RehApp is a Smartphone application that that can contribute to filling the gap in a large variety of types of information related to disability, development, and rehabilitation. It is certainly not the solution to all the information needs of people with a disability and those working in rural and remote parts of low- resource countries, but it can be used to complement services.

However, more is needed to ensure that people with and without disability have access to and make use of essential rehabilitation services. Apart from the development of a quality allied health workforce such as therapists, governments need to invest in the (at times already existing) mid-level rehabilitation workforce including community volunteers, and build their capacity to become multi-functional and multi-skilled agents of change, problem-solvers and liaison persons. Governments, (I)NGOs and (community) colleges need to ensure that these workers have the necessary competencies, are given the right knowledge, skills and - digital - tools and resources to work with, and recognise them as an indispensable part of the workforce for at least the coming decades.

Huib Cornielje

Editor-in-Chief

Disability, CBR & Inclusive Development Journal

Letter from the Editor-in-Chief

Dear Readers,

I would like to start by thanking you for your support to this journal over the years.

Some of you have been readers since its inception over 3 decades ago. I am one of those (old) people whose practical work has benefited from the wide variety of articles that are published. These have been a source of inspiration and have contributed to shaping ideas, vision and practice. Besides, being one among the thousands who read this journal means you realise you are not the last of the Mohicans; it is reassuring to know that there are others who are facing similar challenges and that solutions are also possible for many of those challenges.

For a while this journal has had its home within the Liliane Foundation and we are very thankful for that. However, although publishing a journal could contribute in various ways to the fulfilment of the dream that an organisation may have, it is not part of the core business of most development organisations, including the Liliane Foundation. I have therefore been in discussions for the University of Gondar, in Ethiopia, to take over the responsibility of publishing this journal. In principle there is an agreement to go forward. This development is of pertinent importance as it ensures that the journal becomes the responsibility of a knowledge institute. It also means that in the near future donors need to be found to support the journal financially, as the Liliane Foundation has done so far. While the Liliane Foundation may be willing – at least in the transition phase - to continue to co-fund the journal, there is hope for co-funding by another donor organisation working in the field of disability and development.

This is all positive news but there are no guarantees as yet, especially about the funding. I therefore wish to appeal to you all for help! This can be done in various ways: you could, for instance, convince your organisation to financially support the publication of the journal; you could share ideas with me as editor-in-chief; you could advertise or persuade businesses to advertise in the journal, for which there will of course be some charge. Finally, those who can afford it could financially support the journal with any amount they choose.

I hope that my inbox will soon be flooded with ideas and offers of commitment!

Your editor-in-chief,

Huib Cornielje
(h.cornielje@enablement.nl)

Lived Experiences of Women with Disabilities in Accessing Sexual and Reproductive Health Services in Lira District, Northern Uganda

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ABSTRACT

Purpose: *The study aimed at exploring the lived experiences of women with disabilities in accessing sexual and reproductive health services in Lira district, Northern Uganda.*

Method: *This study utilised a phenomenological study design. Ten women, aged 15 - 49 years, were purposively selected from Lira District Union of Persons with Disabilities. They were accessing sexual and reproductive health services across the district. Data was collected using an in-depth interview guide, and thereafter thematic analysis was done.*

Results: *More than half (60%) of the participants were 40-50 years old and had more than 2 children. Half of them (50%) were married; the majority (70%) resided in the rural area and had a physical disability. They related their positive and negative experiences. On the positive side, they indicated the existence of supportive stakeholders, availability of services, and being served with no discrimination in some health facilities. Negatively, they experienced difficulty in navigating the physical environment in health facilities, lack of transport, negative healthcare provider attitudes, long waiting time, side effects of family planning methods, lack of privacy and unhygienic sanitary environments in health facilities.*

Conclusion and Recommendations: *Women with disabilities in Lira district had both positive and negative experiences in accessing sexual and reproductive*

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health services. Recommendations of this study include counselling women with disabilities about side effects of hormonal family planning methods, incorporating disability studies in curricula for health workers, on-the-job training for health workers on care for persons with disabilities, and enforcing policies that favour access to sexual and reproductive health services for women with disabilities. The government should empower the local leadership to supervise every new health facility that is being constructed, and ensure that accessibility standards for women with disabilities are met.

Key words: *women with disabilities, sexual and reproductive health, lived experiences*

INTRODUCTION

Persons with disabilities still represent a group of people who do not always have equal access to public health programmes and services, despite all the gains made in improving their health status as stated in previous studies (Krahn, Walker & Correa-De-Araujo, 2015). Globally, 15 percent of the world's population lives with some form of disability and women represent more than half of all persons with disabilities (WHO, 2011). Disability is defined as an umbrella term for impairments, activity limitations and participation restrictions. It denotes the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors) (WHO, 2011). It is estimated that 80 percent of people with disabilities are living in low-and middle income countries (LMICs) (Rugoho & Maphosa, 2017). The high prevalence of disabilities in LMICs is partly a result of birth defects, chronic illnesses, accidents, violence and people living longer than before (ACPF, 2014). Women with disabilities constitute a minority group in every society and are more likely to face health, social and economic disparities compared to their counterparts who do not have any form of disability (WHO, 2011). Studies in Sub-Saharan Africa have established that women with disabilities have unequal access to sexual and reproductive health services (Ganle, Baatiema, Quansah & Danso-Appiah, 2020), with 61.3 percent of women with disabilities not able to afford a visit to the health facility (Ganle et al, 2016). Sexual and reproductive health services include maternal and new-born healthcare, family planning services, prevention of unsafe abortion, post-abortion care, management of reproductive tract infections including HIV/AIDS, and the promotion of sexual health (Fathalla & Fathalla, 2014). Women with disabilities face a multitude of

challenges when trying to access such services, including negative perceptions of health personnel, disability-unfriendly infrastructures at health facilities and the absence of trained personnel to provide targeted care to people with disabilities (Rugoho & Maphosa, 2017). Other difficulties include the communication gap, especially when communicating with women who are aphasic, blind or deaf (Masereka, Naturinda, Tumusiime & Munguiko, 2020). This is compounded by the inability of many women with disabilities to protect themselves, the isolation in which they may live, and dependency on others as compared to their counterparts without any form of disability (Spratt, 2013). In addition, false beliefs that women with disabilities are asexual, unsuitable for marriage and unable to manage their fertility or raise children exacerbates the failure of women with disabilities to access sexual and reproductive health services (Spratt, 2013).

In Uganda, despite the availability of sexual and reproductive health services at all levels of healthcare provision, women with disabilities may not have access and those who may have access face challenges such as negative attitudes of service providers, long queues at health facilities, distant health facilities, high costs of services involved, inaccessible physical structures and the general perception in the population that these women are asexual (Ahumuza, Matovu, Ddamulira & Muhanguzi, 2014).

Whereas many studies have explored the challenges faced by women with disabilities in accessing sexual and reproductive health services, few studies have documented their lived experiences.

Objective

This study aimed to explore the lived experiences of women with disabilities in accessing sexual and reproductive health services in Lira district of Northern Uganda.

METHOD

Study Setting

The research was carried out in Lira district, Northern Uganda. The study included women from the Lira District Union of Persons with Disabilities who were availing of sexual and reproductive health services from various health facilities around the district.

Study Design

A phenomenological study design was used. Women with disabilities were asked to recall their past or lived experiences pertaining to accessing sexual and reproductive health services at the various healthcare settings in Lira district.

Study Sample

Women with disabilities were purposively selected and interviewed one after the other until saturation of information was realized when the tenth participant was reached. The study utilised the Washington Group short set of assessment questions on disability to screen, identify and recruit participants (Sloman & Margaretha, 2018). This tool comprises a set of assessment questions from the six core domains of seeing, hearing, walking, cognition, self-care and communication that most often result in activity limitation and participation restriction among individuals. Women who were in the reproductive age group of 15 - 49 years, accessed sexual and reproductive health services earlier and fulfilled the Washington Group short set of assessment questions on disability criterion were included in the study.

Data Collection

Face-to-face interviews were conducted, using an in-depth interview guide that consisted of open-ended questions. The interview guide was translated from English into Lango, which is the local language in Lira district, for better understanding. This was then transcribed verbatim and back-translated into English. The researchers posed questions on the experiences of accessing and utilising sexual and reproductive health services. After asking a question, the participant was allowed to give her opinion on the matter in detail, without interruption; however, prompts to obtain more information were introduced in the discussion. Probes were used, such as silence, urging phrases and non-verbal attending skills. Interviews continued until there was saturation of information. Participants' narratives were tape recorded as well as jotted down in note books. Tape recorded information and written narratives were kept securely in a lockable office cupboard before analysis.

Data Analysis

Transcribed data was analysed manually using thematic analysis. Data was organised into manageable narratives; this was followed by a search for key

concepts and patterns in the narratives. The generated patterns were transformed into themes.

Ethical Considerations

Ethical clearance was obtained from the local Research Ethics Committee at the Uganda Martyrs University. Verbal and written consent was sought from all the study participants.

RESULTS

Socio-demographic Characteristics of Participants

More than half (60%) of the participants were 40-50 years old and had more than 2 children. Half of them (50%) were married, and the majority (70%) resided in the rural area and had a physical disability (see Table 1).

Table 1: Socio-demographic Characteristics of Participants

Characteristics (N=10)	Frequency	Percentage (%)
Age group		
<40 years	4	40
40-50 years	6	60
Marital status		
Married	5	50
Single	5	50
Number of children		
<2 children	4	40
2-5 children	6	60
Residence		
Rural	7	70
Urban	3	30
Type of disability		
Clubfoot	1	10
Amputated upper limb	1	10
Paralysed lower limb	4	40
Hunchback	1	10
Visually impaired	3	30

Lived Experiences of accessing Sexual and Reproductive Health Services

The experiences of women with disabilities were both positive and negative.

The following positive experiences in accessing sexual and reproductive health services were mentioned:

the existence of supportive stakeholders, the availability of services, and being served without discrimination in some facilities. Some participants reported that they received sexual and reproductive health services through Non-Governmental Organisations (NGOs) operating in their areas.

“Sexual and reproductive health information reached me when there were outreaches supported by organisations in our community and I was advised to go to a health facility” (Participant-U).

“On a quarterly basis, Action Aid (an organisation) brought cultural and religious leaders together to speak about gender-based violence and reproductive health in our community. At the end, we got solutions to many reproductive health challenges” (Participant-T).

Participants narrated that they were able to find and utilise sexual and reproductive health services at existing health facilities.

“...When I got to the health facility, there was a health education session going on where I got to know about the various services I could access at the facility” (Participant-U).

“I was able to do cervical cancer screening which otherwise I would not have accessed” (Participant -U).

Being served without discrimination in some facilities was another positive experience mentioned by one participant in particular.

“When I went to deliver my baby, I was served on a first come, first served basis through all the phases involved from registration to discharge” (Participant -J).

“...at the labour room, the nurses were very nice and easy to get along with” (Participant -J).

Negative lived experiences of accessing sexual and reproductive health services related to side effects of family planning methods, navigating the physical environment in health facilities, the lack of transport, negative healthcare provider attitudes, long waiting time, lack of privacy and unhygienic sanitary environments in health facilities.

Participants mentioned side effects such as headaches and vaginal bleeding from using hormonal methods.

"...I used this method where a tiny thin rod the size of a match stick was inserted in my arm after which I started bleeding heavily and also developed headache. This affected me so much since I didn't have any time where I was free from blood-stained panties...." (Participant -X).

Women with disabilities who experienced negative attitudes of the service providers reported that they were not respected in some health facilities. This was evident in the negative attitude of health staff who attended to them.

".... you know, it is like women with disabilities should not conceive at all. When I went for pregnancy check-ups, the way midwives looked at me, was like I have done something wrong! At times they were too rude to me but I learnt to ignore them and just aim at getting someone to check the condition of my baby. We do not like the way society and healthcare providers treat us....." (Participant -Z).

".....when I inquired about an HIV test, the nurse laughed and asked me why I needed it. I felt so embarrassed and only had an HIV test during an antenatal visit. It was like I was immune to getting HIV yet I was in a relationship. I now try not to ask questions as long as they give me the treatment I need when I am sick" (Participant -T).

Participants reported queuing with the rest of the mothers, which made it a much longer wait for services, and they were already experiencing pain from sitting too long. In addition they have to travel back home which takes a long time, especially if they have a limp, or have to crawl home or push themselves in a wheelchair.

"...at the health facility, there can be many patients but very few staff. This particular staff is the one that is giving people medical forms, writing their names and then sending them to the doctor for consultation. There would definitely be a delay....." (Participant -W).

"...at times when I would go for antenatal services, I would line up for a long time and sometimes I would get so tired and give up...." (Participant -Q).

"...our hip bones are not strong enough to stand for a long time and when we are pregnant we tend to feel weak and tired most of the time" (Participant -Q).

Lack of privacy for women with disabilities when visiting health facilities was also mentioned as a deterrent. The respondents felt that their privacy was often violated by health staff.

“When you are blind, they don’t care about privacy. When I was pregnant, I would be examined with even my guide around. This made it difficult for me to talk about my problems with the nurse. When I was examined and I had an infection, I felt embarrassed because even my guide knew about it” (Participant -C).

Most of the health facilities had considerable barriers, both outdoors and indoors, for women using wheelchairs and those with limited walking abilities. This was due to the absence of ramps, rails and multi-storey buildings without elevators.

“...the health facility did not have ramps to help those on wheelchairs like me. One day I went there and I had challenges negotiating my way around the buildings. The nurses who could have helped me also had lots of other patients to manage, which left me frustrated “ (Participant – P).

The absence of adjustable delivery beds made it difficult for women with disabilities to receive good quality maternity services and take full control of their birthing process.

“I found difficulty getting onto the bed at the hospital when I went to deliver. My attendant helped me up and down the bed which made me feel like a burden to her” (Participant –J).

Women narrated that sanitary facilities in the health facilities were completely inappropriate, inaccessible and unhygienic. There were no latrines designated for women with disabilities. This affected their hygiene since not everyone is very conscious about keeping sanitary facilities clean.

“... I face a lot of problems when it comes to using the toilets and latrines. For some of us, who crawl, the toilet floors are very dirty and it is difficult for us to squat on the toilets and latrines without sitting pans...” (Participant –W).

Movement to and from the health facility was reported to be challenging for women with disabilities. Major concerns related to transport, including the lack of support to make use of transport, the difficulty in finding transport and the high costs involved.

“...I had to pay the person to accompany me to the health facility and also pay for my own to travel to the health facility. Considering that I don’t have a meaningful job, it is difficult” (Participant-O).

“...I sat behind a truck with no proper support for me while travelling from home to town to access the health facility, which was not very comfortable for me” (Participant-O).

“.....I needed somebody to push me, especially with our bad roads...” (Participant -J).

DISCUSSION

This study identified a number of positive and negative experiences of women with disabilities in accessing sexual and reproductive health services. Among the positive experiences were:

1. The availability of supportive stakeholders who contribute financial aid to support social mobilisation campaigns, as well as outreaches to bring services closer to women with disabilities. (Nxumalo, Goudge & Thomas, 2013).
2. The existence of sexual and reproductive health services in various health facilities reduces demoralisation for women with disabilities. It builds trust in the facility and increases chances that women will come back to utilise the service when next required.
3. Being attended to without discrimination improves service attendance by women with disabilities (Ganle et al, 2020).

Women with disabilities had negative perceptions about family planning services, especially the hormonal methods that were being offered. The negative perceptions resulted from the adverse side effects experienced after taking contraceptives, including headaches, heavy bleeding and abnormally long and short menstrual cycles. This finding is consistent with a similar study carried out in Mexico (Dansereau et al, 2017) where women feared long-term infertility impacts, such as fears of harming the baby or difficulty conceiving. Being afraid that the uterus and ovaries could be harmed or altered after use of contraceptives was mentioned in the Mexican study as well (Dansereau et al, 2017).

The reported negative attitudes of health workers towards the provision of sexual and reproductive health services to women with disabilities can contribute

to the impression that health workers do not value these women equally, like other clients, during provision of services. This alters the perceived quality of sexual and reproductive health services provided to them (Tunçalp, et al, 2015). Similarly, studies conducted in Kenya and Uganda have shown that women with disabilities felt disrespected by service providers and this is seen as an indication that members of the community view women with disabilities as not having sexual feelings; as not being able to get pregnant, and as women who should not get married (Apolot et al, 2019). These perceptions held within many communities paint a picture of how women with disabilities are viewed when they seek sexual and reproductive health services. Studies carried out in Nepal and Uganda found that health workers not only have a negative attitude towards women with disabilities, but are also not trained to appropriately handle special needs of women with disabilities (Morrison et al, 2014; Lee et al, 2015).

In this study it became clear that women felt their privacy was compromised when making use of sexual and reproductive health services at health facilities. The finding that women with disabilities would be examined in the presence of their assistants or helpers is similar to a study in Zimbabwe which found that health workers did not know how to relate to women with disabilities, especially in the presence of their helpers (Papp et al, 2014; Rugoho & Maphosa, 2017). In such cases, women with disabilities would feel disrespected, which is a serious hindrance in providing quality healthcare. As such, women with disabilities may feel dissatisfied, thus reducing the chances of seeking sexual and reproductive health services again.

The opinions expressed by women with disabilities in the current study indicate the range of difficulties they encountered in navigating the environment and routes at health facilities, being unable to climb on to delivery beds and being unable to squat on the available toilets at the health facilities. The most notable barriers for women with disabilities in accessing health facilities were the lack of ramps for wheelchairs, high stairs and the lack of personnel to assist them in climbing stairs, narrow doorways, and inaccessible toilets. Similar findings have been reported in other studies (Ahumuza et al, 2014;). Findings from this study suggest that though much has been done to improve access to sexual and reproductive health services for women with disabilities, a lot still needs to be done to mitigate challenges and the aforementioned barriers to access such services. Improvements that are needed to create disability-inclusive services require a multi-sectoral and multi-disciplinary approach, due to the different types of barriers that prevail.

In this study, challenges related to transportation include the lack of suitable means of transport, lack of support to access transport, difficulty in finding transport and the high cost of transport. Similar results can be found in other studies (Sakellariou & Rotarou, 2017; Dassah, Aldersey, McColl & Davison, 2018; Apolot et al, 2019). The problems related to transport seem to be aggravated because many women with disabilities are poor (Pinilla-Roncancio, 2015; Naami, 2015).

CONCLUSION and RECOMMENDATIONS

Women with disabilities have both positive and negative experiences in accessing sexual and reproductive health services. On the positive side, women mentioned the existence of supportive stakeholders, availability of services, and being served without discrimination in some health facilities. Negatively, participants elucidated challenges related to side effects of family planning methods, difficulty in navigating the physical environment in health facilities, lack of transport, negative healthcare provider attitudes, long waiting times, lack of privacy and unhygienic sanitary environments in health facilities.

It is recommended that providers of sexual and reproductive health services address the side effects resulting from the use of hormonal family planning methods through appropriate information, education and management. The researchers propose also that healthcare personnel have relevant competences to work with women with disabilities; that curricula of health workers pay sufficient attention to the life and needs of women with disabilities; and that the current workforce of healthcare personnel be given on-the-job training in providing appropriate care for persons with disabilities in order to improve their attitudes towards women with disabilities. For every new healthcare facility being constructed, the government should ensure that accessibility standards for women with disabilities are being met. Favourable policies that ensure access to sexual and reproductive health services for women with disabilities should be developed, and necessary actions to ensure their implementation should be put in place.

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“HIV is a Story, not Life”: Resilience among South Asian Women living with HIV in Canada

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ABSTRACT

Purpose: *This study aimed to understand how immigrant South Asian women living with HIV in Canada develop resilience and to identify their self-management strategies. These strategies could be used by marginalised women and can be supported by health providers.*

Method: *The study participants were eight South Asian women with HIV, living in Ontario, Canada. The women belonged to an urban HIV community organisation. Qualitative methods were used to investigate their experiences. In-depth face-to-face interviews were conducted, utilising a photo/object elicitation technique, to identify the strategies used to develop resilience.*

Results: *The women were primarily in mid-adulthood (age range 39-60 years) and had lived for many years with HIV (range 8-25 years). Thematic analysis of the interview transcripts revealed three themes characterising strategies for resilience: identifying the need for self-care, maintaining social connectivity, and remaining optimistic.*

Conclusion and Implications: *With these strategies, the women had cultivated strength and perseverance in adjusting to adversity. Viewing the resilience of South Asian immigrant women living with HIV through a cultural lens could help to understand and facilitate the development of culturally acceptable self-management strategies.*

Key words: *resilience, South Asian, women, HIV/AIDS, disability*

INTRODUCTION

The early provision of antiretroviral treatment has significantly increased the life expectancy of people living with HIV (Yang, Beymer, & Suen, 2019). Individuals living with HIV may experience the premature onset of comorbidities such

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as diabetes, heart disease, obesity, metabolic disorders, stroke, osteoporosis, osteoarthritis, inflammatory arthritis and cancer (O'Brien, Wilkins, Zack, & Solomon, 2010). They can also experience health-related challenges due to HIV infection and the side effects of medications, such as fatigue, diarrhoea, nausea, muscle weakness, decreased muscle mass, stress, depression, lipodystrophy, neurocognitive impairment and peripheral neuropathy (Snowden et al., 2017; Squires et al., 2011). Moreover, an HIV diagnosis itself may impact an individual's psychosocial well-being, in part due to HIV stigma and discrimination which may result in HIV-related disability (Dale et al., 2009; O'Brien, Bayoumi, Strike, Young, & Davis, 2008).

Disability is defined as impairments in body structure or function, activity limitations, and social participation restrictions that influence individual and societal perspectives (Stucki, 2005; World Health Organisation, 2007). The Episodic Disability Framework builds on the International Classification of Function and Disability and was derived from the perspectives of people living with HIV (O'Brien et al., 2008). The Episodic Disability Framework was designed to capture the health-related challenges and potential fluctuations in these challenges that may be experienced by adults living with HIV (O'Brien, Davis, Strike, Young, & Bayoumi, 2009).

The Framework consists of three components - dimensions of disability, contextual factors, and triggers of disability (O'Brien et al., 2008). Dimensions of disability in the Episodic Disability Framework include physical, cognitive and mental-emotional symptoms and/or impairments, difficulties in carrying out day-to-day activities (e.g., household chores), challenges to social inclusion (e.g., employment, personal relationships), and uncertainty or worrying about the future (O'Brien et al., 2008). The contextual factors of disability include intrinsic (e.g., living strategies and personal attributes) and extrinsic factors (e.g., social support, stigma) that may influence the dimensions of disability (O'Brien et al., 2009).

In Canada, South Asian women constitute a small but increasing number of people living with HIV (Haddad, Li, Totten, & Mcguire, 2018). However, their experiences of living with HIV and the resulting disability remain understudied. Understanding the experiences of South Asian women living with HIV is particularly important because they may be more disadvantaged than others who are living with HIV in high-income countries and are embedded in Canadian societal contexts. In South Asian culture, women are gatekeepers of family honour

(Vlassoff & Ali, 2011) and may not disclose their HIV status because of their community's lack of understanding about HIV and the community's tendency to blame and stigmatise women for their HIV status (Hawa, Underhill, Logie, & Loufty, 2018). Immigrant South Asian women who are legally sponsored by their husbands are at an increased risk for intimate partner violence (Ahmad, Driver, McNally, & Stewart, 2009). In addition, economic dependence, residency status, and societal norms such as silence, obedience and subordination, combined with fear of divorce and anxiety about their children's future, may also compromise South Asian women's ability to disclose their HIV status (Finfgeld-Connett & Johnson, 2013; Majumdar, 2013; Zhou, Majumdar, & Vattikonda, 2016). A previous study (Vajravelu, O'Brien, Moll, & Solomon, 2022) demonstrated that South Asian women living with HIV experience intersecting vulnerabilities such as intimate partner violence, gender norms, HIV-stigma, and racism. Little is known about strategies that these women use to cope with day-to-day challenges, and how these are shaped by the individual and social contexts in which they live. Understanding their experiences and coping strategies may provide insights into how South Asian women with HIV develop resilience.

Resilience is a positive adaptation which helps an individual to overcome threatening situations (Earnshaw et al., 2017). Studies examining resilience among people living with HIV suggest that coping strategies such as social support and intrapersonal skills have a positive impact on their psychological well-being (Betancourt, Meyers-Ohki, Charrow, & Hansen, 2013). However, there is a dearth of scholarly knowledge on resilience among South Asian women living with HIV in Canada.

Objective

The purpose of this study was to understand and identify the self-management strategies used to develop resilience among immigrant South Asian women living with HIV in Canada. Their coping strategies could be followed by marginalised women and can be supported by health providers.

METHOD

Study Design

An interpretive phenomenological approach was adopted to explore the lived experiences of immigrant South Asian women living with HIV. Interpretive

phenomenology focuses on describing the experiences of individuals and how these influence the choices they make (Lopez & Willis, 2004; Pietkiewicz & Smith, 2014).

Sample Size

For a phenomenological study, Morse (2000) recommends a sample size that is small, yet provides an in-depth understanding of participant experiences. In the current study, each participant was invited to attend two interviews that incorporated photo elicitation, thereby producing a large set of in-depth data for analysis.

Participants

Women were recruited from a community-based HIV service organisation in Toronto, a large urban city in Ontario, Canada, which provides HIV, sexual health, and support services for South Asian communities (Alliance for South Asian AIDFS Prevention - ASAAP, 2014). English-speaking women who self-identified as South Asian, aged 18 years and older, who had been living in Canada for more than 3 months, were included. Purposive sampling was used (Burmeister & Aitken, 2012; Coyne, 1997; Mason, 2010) to ensure participants possessed similar gender and cultural attributes.

Data Collection

A demographic questionnaire was administered prior to the first interview. Face-to-face semi-structured interviews were conducted with participants. A semi-structured interview guide was developed based on the Episodic Disability Framework, with open-ended questions to explore concepts related to health, illness, the role of culture, HIV stigma, discrimination, and their unique experiences as South Asian women living with HIV in Canada. After the initial interview, participants were asked to return for a second interview to glean additional in-depth information. The interview guide for the second interview was developed based on gaps identified in the first round of interviews, including questions about racism and intimate partner violence. During the second interview, a photo/object elicitation technique was used to stimulate dialogue in which participants were asked to bring a picture or object that was 'meaningful' for them to the interview (CohenMiller, 2018; Harper, 2002). This helped in obtaining concrete and detailed information about how personal and social contexts shaped their experiences. All interviews were audio-recorded and transcribed verbatim.

Data Analysis

A thematic analysis approach was used (Vaismoradi, Turunen, & Bondas, 2013) that focused on examining personal strategies and contextual factors that shaped patterns of resilience. Analysis progressed from dwelling on the text to search for meaning, on to interpreting the words, phrases, and sentences, and finally to synthesising ideas to identify key themes related to resilience (Davidson, Paulus, & Jackson, 2016; Sutton & Austin, 2015). Two investigators (SV and PS) independently coded two transcripts of the initial interviews using line by line coding and developed a codebook to describe each code. Using the codebook, they independently coded the remaining transcripts, meeting periodically to reconcile differences. The second set of interview transcripts were reviewed and coded independently by both these investigators, using a similar analytic process. Final categories and themes were developed through consensus of all members of the research team. A qualitative software programme called NVivo11(QSR International, 2017) was used to manage the data and support the analysis.

Ethics

This study received research ethics approval from the Hamilton Integrated Research Ethics Board (Project number: 1789). All the participants provided written informed consent.

RESULTS

Participant Demographics

Eight women participated in the initial interview. Six of them agreed to participate in a second interview (14 interviews in total). All participants were first-generation South Asian immigrant women, who had been living in Canada for an average of 24.2 years (range 6 - 44 years, standard deviation (s.d.) ± 10.2). The mean age of the women was 47.1 years (range 39 - 60 years) and the mean length of time since HIV diagnosis was 15.1 years (range 8 - 25 years). Two women identified as single (25%), three were married (37.5%), one was widowed (12.5%), and two were divorced (25%). Five women (62.5%) lived with a partner or children, and three (37.5%) lived alone. Five women were employed (62.5%), while three (37.5%) were unemployed. Among the eight participants, two had disclosed their HIV status to select family members.

Participants were women of South Asian ethnicity who had immigrated to Canada from India, parts of Africa, South America, the Caribbean, and Southeast Asia. All participants were first generation South Asian immigrants. Two women had come to Canada when they were young (two-and-a-half years old). Seven participants were infected with HIV by their partners or husbands, and one participant was infected through blood transfusion.

Building Resilience

Women coped with and adapted to challenging situations and reconstructed their priorities and reshaped their identities while living with HIV. Resilience is a process of bouncing back from an adverse situation by adopting certain positive living strategies (Fine, 1991). All the women demonstrated one or more resilient qualities. Resilience was developed in several ways. The data analysis resulted in three themes pertaining to strategies used to develop resilience among South Asian women living with HIV, namely: identifying the need for self-care, maintaining social connectivity, and remaining optimistic. These themes are described below with representative quotes.

i. Identifying the Need for Self-care

Women living with HIV identified the need for, and importance of, positive adaptive measures such as self-care, to enhance resilience. Most of the women aspired to maintain good health. While describing their coping strategies, it was evident that they proactively engaged in activities to maintain their health. For example, one woman shared that her routine included:

“Exercising, eating healthy and involving myself in the community and volunteering, working and everything” (Participant 6, age 58, diagnosed with HIV 8 years ago).

Participants’ stories highlighted the importance of self-care as a strategy to support resilience. South Asian women often live with strict gender roles and are unable to rest or negotiate their chores in the family; this may contribute to further deterioration in their health and affect their role as caregivers. A woman who was working part-time shared her experience:

“Yeah, because in our culture we housewives have the responsibility to take care of our whole house. In my own life, my husband is positive, and I’m also positive; he doesn’t do the housework and I’m the one who has to do (it)” (Participant 2, age 46, diagnosed with HIV 15 years ago).

Despite strict gender norms, women learned to be independent in managing their self-care. Those who did not receive support from their family or the South Asian community, found that self-reliance was the only conceivable way to manage their stress. This sense of confidence contributed to their resilience.

“I’m the only one to pick myself up and bring myself back to reality and nurture myself” (Participant 7, age 46, diagnosed with HIV 16 years ago).

Gender and primary caregiver roles demanded that women perform their everyday chores in spite of health challenges. For some, this contributed to the deterioration of their physical and mental health. A woman who was a single mother and a full-time employee mentioned that due to her health challenges it was difficult to perform her day-to-day activities at home, which eventually affected her parental role.

“And I’m tired. I used to have the energy to do my housework, but now when I come in (home) my body says ‘no, you can’t’. I like to clean my place on Friday. Like yesterday I didn’t do my housework and now my house is a mess. And when you see that also you don’t feel comfortable. Where do I start and what do I do? But being a parent there is only so much you can ignore!” (Participant 7, age 46, diagnosed with HIV 16 years ago).

The women incorporated self-management strategies to reduce stress and build resilience. They described their strategies, developed over time, to gain personal control and mastery over their condition. For example, when asked ‘who is important in your life?’, one woman, who was living alone with her daughter, showed a picture of her pet hamster to emphasise its positive impact on her life.

“I bought that hamster because I am lonely, and I feel that can give me some kind of way I’ll get some happiness” (Participant 4, age 44, diagnosed with HIV 8 years ago).

The experience of immigration added another layer of complexity and stress and had a negative impact on the mental health of some women. Though they considered immigration to Canada as a better option for their standard of living, they found it difficult to adapt to the new culture. One woman explained that along with her health challenges, the fast-moving Canadian lifestyle and work system had predisposed her to depression.

“I was diagnosed (with) depression a month ago, maybe that’s because of this new place as an immigrant or (maybe because of) health issues. And again,

the way I work back home is different. Here I have to (cope with) the Canadian system, all these things have given me too much stress” (Participant 2, age 46, diagnosed with HIV 15 years ago).

Over time the women engaged in strategies to heighten feelings of personal control and mastery over their condition. Many of them stated that living in Canada had taught them to be self-reliant. They had learnt how to seek multiple resources, access information to make informed decisions about their health and expand their social boundaries. One woman showed a picture taken during her Canadian Citizenship ceremony and said:

“Here (in Canada) I learned how to be myself, I have many kinds of knowledge to take care of myself” (Participant 6, age 58, diagnosed with HIV 8 years ago).

Women’s stories often portrayed their transformation into confident and autonomous individuals. It was evident that their self-reliance and confidence stemmed from their life experiences.

“I don’t let other people lead my life. So, because of that, I see myself even healthier and happier” (Participant 4, age 44, diagnosed with HIV 8 years ago).

The stories revealed that although these women struggled with health challenges, isolation and depression, the support systems available in Canada had shaped their confidence and enabled them to be self-reliant and engage in self-care.

ii. Maintaining Social Connectivity

The participants reported that they often experienced isolation due to their HIV diagnosis. As HIV is a stigmatised disease, it was hard for them to talk about their disease or request support. One woman explained that stigma was one of the reasons for her social isolation:

“In our community, it’s very hard to be open, we are being isolated a lot” (Participant 8, age 39, diagnosed with HIV 18 years ago).

After their HIV diagnosis, the women purposefully reconstructed their social supports, such as becoming active members of HIV-related organisations or groups, utilising media to connect with friends, and maintaining close relationships with family. One woman had established various formal and informal support systems, including social media, to boost her resilience.

“I look for people, I read things that people post, even on Facebook. I read something, so I take those things as lessons or signs to me like ‘hey chin up, it’s going to be okay’ ” (Participant 1, age 44, diagnosed with HIV 8 years ago).

Women also reported that due to stigma, many HIV positive South Asian women are hesitant to access services from AIDS Service Organisations (ASOs). This is primarily due to the fear of being identified as an HIV positive person by someone in the South Asian community. When asked about HIV stigma, a woman mentioned:

“Yes, Stigma is everywhere, not only in Canada. The stigma is everywhere. That’s why people don’t come out and tell that they have HIV. Especially the South Asians, they never disclose their HIV status. I know lots of South Asian women who are HIV positive, but they don’t even come (to the ASO) here. Because they are afraid if somebody finds out. Stigma is a big thing” (Participant 1, age 44, diagnosed with HIV 8 years ago).

Though women intentionally severed social connections due to HIV stigma or fear of stigma, they purposefully rebuilt connections with individuals whom they trusted. Women mentioned that identifying as a member of an HIV organisation offered them a sense of connectedness. For many, these friendships provided a sense of belonging.

“I have our peers, (and) there are some folks within our community. They are quite sweet. They check in with us (and ask), ‘how are you feeling? Why are you working so hard?’” (Participant 1, age 44, diagnosed with HIV 8 years ago).

The social supports offered in Canada helped the women to develop resilience. Though they experienced difficulties as immigrants, they acknowledged the benefits of the social networks that were not available in their home countries.

“Here you get help. You have services, organisations. Back home, I don’t think you would have any kind of education or any groups. And here there are services to help you out. But in our countries, probably it would be a dark hole” (Participant 8, age 39, diagnosed with HIV 18 years ago).

Women used selective resources to maintain their social connectivity. Those who were employed explained that interacting with others in their work environment was a welcome distraction as it stopped them from thinking about their problems and helped to build their confidence. For a few women, merely maintaining contact with family was beneficial; for others, family members provided concrete

assistance and were their main social support. One woman showed a picture of her family and described the comfort and practical or emotional support she received from her family following her HIV disclosure.

“So at least, when I really need help, my family is there for me. I always get support from my mom” (Participant 4, age 44, diagnosed with HIV 8 years ago).

Women mentioned that after their HIV diagnosis they learnt to rearrange their priorities and identities. Most of them gave priority to their families because it provided a sense of identity and purpose. When asked, “who is most important in your life?”, one woman showed a picture of her family and said:

“And the support which I’m getting from them (family), it’s so much. I really appreciate. So that’s what it is for me, these are so important in my life” (Participant 7, aged 46, diagnosed with HIV 16 years ago).

Women described the positive relationships that they built with their healthcare professionals and said they were comfortable sharing their experiences with them. They developed confidence to make decisions about their healthcare as they believed their healthcare professionals would be non-judgemental and would protect their privacy.

“You’re safe in Canada about it (being diagnosed with HIV) and you have all the health care in Canada (for HIV) and support. So, the safety is here in Canada, oh not like back home” (Participant 2, age 46, diagnosed with HIV 15 years ago).

iii. Remaining Optimistic

Racial discrimination was viewed as another potential contributor to mental health challenges, affecting self-esteem and confidence, and predisposing them to depression. One woman, who experienced discrimination at work, described her feelings of depression and isolation:

“I’m struggling at work until now. But, before it (racial discrimination) was hard, I was taking it (racial discrimination) seriously. I even got sick, I was depressed, I was at home” (Participant 7, age 46, diagnosed with HIV 16 years ago).

In spite of the racism and HIV-stigma that the women faced, being optimistic helped them to build resilience. Although they experienced feelings of isolation and depression, their narratives revealed that they made conscious efforts to

remain hopeful and positive. For some women, religion or spirituality served as a source of emotional support and guidance.

“Yes, I do prayers a lot, that gives me the power to live, it’s making me strong”
(Participant 3, age 53, diagnosed with HIV 23 years ago).

Women who feared discrimination due to their HIV diagnosis could not receive support from their family or friends. However, they created their own comfort zone. One woman, who was betrayed by her intimate partner and neglected by her family, showed a picture of a painting on her wall, and described how she created a positive and safe environment for herself.

“Oh, this picture is in my house, and it reminds me of being somewhere warm. Whenever I come home from a hard day or whatever, feeling sad or depressed, that I can just look around in my house especially at this photo, and know that I have some kind of warmth or happiness around me” (Participant 8, age 39, diagnosed with HIV 18 years ago).

Most women experienced discrimination based on the colour of their skin, as part of their daily life. One woman described how she experienced racial discrimination while travelling by train or bus:

“For example, if I take the TTC, you know, there might be a Canadian Caucasian. They might look at you, and the way they look at you... If you go somewhere, and you have to do anything, if you need some help, the way they talk to you, they talk down to you” (Participant 8, age 39, diagnosed with HIV 18 years ago).

However, women built their resilience by positive thinking and by setting meaningful goals. They wanted to contribute to communities in a positive way, instead of focusing on their own problems. They developed the ability to cope with their challenges and wanted to accomplish their goals. One woman shared her plans for the future:

“I might pursue a degree in law. I think that’s the logical step for me, in terms of understanding some of the legal problems for the people living with HIV”
(Participant 1, age 44, diagnosed with HIV 8 years ago).

Most women accepted their HIV status and described moving forward in life, a positive indication of their resilience. One woman said, *“HIV is a story, not life”*, which demonstrated that she was able to maintain a balanced perspective and positive outlook.

Women learned to 'pick themselves up' from challenging situations and positively reconstruct their identities. One woman explained her ability to manage her illness by showing a kaleidoscope during the meaningful object/picture exercise and saying:

"Whenever I was very down, I used to look at this (kaleidoscope). Every time I look at this, it's a different kind of pattern. That's why it is very special. I think it's important to me because it will apply to the overall philosophy in my life. I sometimes think that if we really tried, we could put ourselves in anyone's shoes. That means even with people that otherwise we don't associate with" (Participant 1, age 44, diagnosed with HIV 8 years ago).

Many participants acknowledged their anxiety related to stigma and health. However, these difficult situations often helped them to develop inner strength to navigate challenges and rediscover new meaning in life. One woman narrated how her perceptions about HIV changed over time:

"I take (everything) as a positive thing. I do not take things as a negative thing, even being HIV positive. Being HIV positive made my life different; made my life like thinking about others, not being selfish, being selfless" (Participant 7, age 46, diagnosed with HIV 16 years ago).

DISCUSSION

Results from this study revealed that South Asian women living with HIV in Canada actively used strategies to develop resilience and cope with the challenges they experienced as immigrants and racialized women. Participants described how they adjusted after their HIV diagnosis and resolutely rebuilt their lives in Canada. This ability to selectively address stressors was supported by Perrett and Biley (2013) who claimed that resilience does not develop automatically but is a conscious process involving choice and subsequent action.

Women utilised self-care strategies to nurture their physical and mental well-being. This finding is consistent with Singh, Hays, Chung and Watson (2010) who reported that self-care enabled immigrant South Asian women who experienced childhood sexual abuse to set healthy boundaries and make informed decisions. Furthermore, intentional self-care can heal one's mind, body and spirit (Singh et al., 2010). Ahmad, Rai, Petrovic, Erickson and Stewart (2013) also reinforced those South Asian women who were survivors of intimate partner violence transformed themselves through self-care and involvement at work, which allowed them to move forward in their lives.

The theme of social connectivity attests to the fact that women in this study were aware of the importance of other people in their lives. They valued their families greatly and were worried about the possible lack of family support following disclosure. However, they understood that social support could come in many forms and had rearranged their social connectivity following their HIV diagnosis. Most women were part of a peer group involving South Asian women living with HIV at a community-based organisation; this fostered their resilience through a sense of belonging, support, and compassion from others. Logie, James, Tharao and Loutfy (2011) also found that resilience among women of colour living with HIV was strengthened by building peer supportive HIV-positive networks. Earnshaw et al. (2017) suggested that social support can help in reconstructing and reframing individual thoughts since participants can talk through events in a safe environment. Similarly, immigrant South Asian women who experienced intimate partner violence built their resilience by expanding their social networks and connections with people they trust (Perrett & Biley, 2013).

South Asian women living with HIV who participated in this study were able to maintain a positive outlook on their lives. Similarly, a sense of optimism was identified among women living with HIV in Thailand (Liamputtong & Haritavorn, 2012). The current study also suggests that women's perseverance and willingness to struggle along have reconstructed their lives and identities in a positive way. These findings are consistent with Emlet, Shiu, Kim and Fredriksen-Goldsen (2017) who observed that adults living with HIV who tried to maintain a positive outlook were better able to overcome adversity.

The current study's findings contribute to the under-researched area of resilience among South Asian women living with HIV. Results align with those of Singh (2009) and Zafar (2015) who asserted a need for a resilience framework for ethnic minority women that includes the influence of culture. This is important because the current model of resilience was built on western values which are focused on individualism and individual factors influencing resilience (Zafar, 2015), whereas South Asian culture reinforces collectivism. There is a need to understand relational resilience, as South Asian culture promotes familial social support (Zafar, 2015).

This study has implications for health and social service providers. A growing body of literature suggests that rehabilitation services can reduce disability and improve the quality of life of people living with HIV (Brown, Claffey, & Harding, 2016; Li et al., 2017; Mkandla, Myezwa, & Musenge, 2016; O'Brien et al., 2016). The

current study's findings highlight the importance of ensuring culturally relevant rehabilitation services that address the multi-dimensional nature of disability. For example, one evidence-based HIV rehabilitation approach focuses on increasing physical activity. South Asian women may perceive exercise beyond daily work as a selfish self-care activity (Lawton, Ahmad, Hanna, Douglas, & Hallowell, 2006; Lucas, Murray, & Kinra, 2013); therefore, cultural norms may prevent them from engaging in or joining a sports team or using local leisure facilities for sports or games (Lawton et al., 2006). This reluctance points to the need to explore alternative, culturally relevant approaches to promote physical activity such as Zumba, Tai-chi programmes, dance, or yoga. If these activities are organised through collaborations with community and faith-based organisations, they may provide a more welcoming and culturally appropriate environment (Lawton et al., 2006).

Resilience strategies that can be practiced by individuals living with a chronic illness such as HIV, include negotiating uncertainty and regaining optimism by cognitively reflecting on the past and creating new goals (Perrett & Biley, 2013). Managing HIV also requires engagement in self-care and advocacy (De Santis, Florom-Smith, Vermeesch, Barroso, & DeLeon, 2013). Researchers recommend the utilisation of community-based exercise programmes along with self-management strategies for people living with HIV (Li et al., 2017). In particular, group-based exercise was found to increase social support and adherence to exercise participation, suggesting that exercise programmes may have both physical and psychosocial effects for people living with HIV (Li et al., 2017). Hence, implementing community-based non-traditional rehabilitation, through community service organisations, could provide physical and social support to South Asian women living with HIV. Community-based organisations often offer advocacy and programmes to promote resilience among people living with HIV. It is important that rehabilitation providers understand the social support networks of South Asian women living with HIV in order to facilitate positive connections with peers and promote resilience.

Strengths

The strengths of this study included two interviews with the participating women, as this provided rich data which offered greater scope for analysis. Triangulation of data sources through photo elicitation added further depth to the investigation into the resilience among participants. Photo elicitation technique was an effective

tool to facilitate in-depth understanding and provided scope for discussion of the women's lived experiences. To be specific, the women were hesitant to discuss certain sensitive issues such as racism and intimate partner violence in detail. Photo elicitation technique helped to probe these sensitive topics and convey complex experiences. The study participants presented pictures that they felt were 'important' in their lives and actively engaged in the discussion; this helped the researchers to understand their resilience amidst the adversity they were experiencing. Application of the Episodic Disability Framework (O'Brien et al., 2008) to the lived experience of South Asian women living with HIV strengthened this study as it helped to understand the multidimensional disability experiences of the women.

Limitations

Limitations included the recruitment of participants from only one HIV community organisation in an urban setting, and inclusion of only English-speaking immigrants. Women who do not access HIV organisations, do not live in urban centres, and do not speak English may be more socially isolated or, alternatively, may be better able to cope with their health challenges. Further research is needed to understand resilience strategies of women who do not use HIV organisations or live in more rural or remote areas.

CONCLUSION

The study findings can be utilised by researchers and healthcare practitioners to understand the resilience of South Asian women living with HIV and other marginalised populations who may share a similar cultural background.

South Asian women living with HIV in this study exhibited resilience, cultivated through strength and perseverance in adjusting to adversity. In spite of the complex challenges they faced, they opened up new pathways to living by building self-care strategies, rearranging their social connectivity, and practicing optimism. Understanding the resilience of racially marginalised women living with HIV through a cultural lens could help to facilitate the development of culturally acceptable self-management strategies.

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Developing an Assessment Tool for Post-Surgical Paediatric Rehabilitative Care in Tanzania: an Interprofessional Approach

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ABSTRACT

Purpose: Located in Arusha, Tanzania, The Plaster House provides rehabilitative services to children receiving surgical care for treatable disabilities. This article describes a set of outcome measurements developed in a collaborative relationship between an evaluation team from The Plaster House staff and St. Catherine University faculty, focused on effectively and efficiently collecting post-operative evaluation and outcome data from a rehabilitative care facility for children with treatable disabilities.

Method: From seven care pathways utilised for surgically treatable disabilities (cleft lip and palate, spina bifida, skeletal fluorosis, osteomyelitis, burns, clubfoot and hydrocephalus), an interactive process led to the development of a medical assessment tool for monitoring and evaluation with limited electronic health record and staffing capacity.

Results: The medical assessment tool serves multiple purposes for the rehabilitation programme, including monitoring participants' progress, evaluating the effectiveness of current practices, and sharing data with stakeholders. The tool includes collection of demographic and background information, one to three diagnosis-specific indicators to measure progress, and three questions related to typical development (activities of daily living, play, and social interaction).

Conclusion and Implications: Due to the delayed ability to conduct a site visit, the evaluation team relied heavily on effective communication to sufficiently relay challenges and successes in developing and implementing the tool. The proposed medical assessment tool developed by an interprofessional team has

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the potential to feasibly capture post-operative outcome measurements during rehabilitative care.

Key words: *children with disabilities, medical assessment, monitoring and evaluation, outcome measurements*

INTRODUCTION

Over 5 billion people lack access to necessary surgical intervention (Butler et al, 2017), and the majority of these individuals reside in regions of the world with small clinician to population ratios and under-resourced healthcare facilities (Philipo, Nagraj, Bokhary and Lakhoo, 2020). As a result, health inequities are present, as both socioeconomic status and public health infrastructure hinder access to adequate care, especially for those in remote areas (Taylor, Forgeron, Vandyk, Finley and Lightfoot, 2021). There are large numbers of children with surgically treatable disabilities, who go untreated each year (Butler et al, 2017; Hendriks et al, 2019). Infancy and early childhood are crucial time points for rehabilitative surgical interventions. When treatable disabilities are neglected during years of critical development, they have the potential to increase lifelong disability and contribute to early mortality (Butler et al, 2017).

In countries like Tanzania in East Africa, the shortage of surgeons and the handful of specialty hospitals and centres in a geographically large country severely limit the access to paediatric surgery (Butler, 2016; Lelli Chiesa et al, 2020). The number of surgeons, obstetricians and anaesthesiologists (SOA) falls short of the recommendations set by Tanzania's Ministry of Health, for 20 SOA per 100,000 population, with a ratio of 0.46 per 100,000 population (Ministry of Health Community Development, Gender, Elderly and Children, 2018; Philipo et al, 2020). In addition to training a larger clinical workforce, some Tanzanian hospitals and universities have formed international partnerships with universities and medical entities to reduce the burden of surgical need (Philipo et al, 2020). Additionally, non-governmental organisations (NGOs) fill gaps in paediatric surgical care and rehabilitation (Taylor et al, 2021). Faith-based missions, short-term surgical trips, academic partnerships, and teaching workshops have also played roles in addressing the paediatric surgical gaps in Tanzania (Butler et al, 2017; Hendriks et al, 2019).

The World Health Organisation (WHO) recommends the increased use of pre- and post- surgical assessment tools (World Health Organisation, 2021) to assure

quality and appropriate client follow-up. Assessments and evaluations are an essential part of the perioperative plan of care. These assessments are often not a standard part of perioperative care in low-resource areas like Tanzania, as a lack of financial resources and trained personnel impede implementation (Butler et al, 2017). The lack of widely available pre- and post-operative assessments decrease the availability of data to measure progress and performance post surgery. Strengthening monitoring and evaluation data collection methods across a healthcare organisation or system often requires the implementation or the upgrading of electronic systems that can be used to capture the data (Luan, Mghase, Meyers and Chang, 2021). An additional barrier is the complexities of capturing data for measures of physical progress that require medical training and expertise (Hendriks et al, 2019).

While there are numerous global initiatives to increase access to paediatric surgical care and rehabilitation in low-resource areas, many of these are unpublished, creating an absence of literature on the subject (Lelli Chiesa et al, 2020). While standards of care have been set by the WHO for the intraoperative period, there is a paucity of provisions for perioperative care and rehabilitation. The use of perioperative assessment tools helps to ensure safety and promotes the success of various procedures in the long term. These assessments are not only useful for monitoring individual cases, but can be used to identify gaps and needs within systems themselves (de Oliveira Pires, da Luiz Goncalves Pedreira and Peterlini, 2013). Therefore, a need for the development of post-surgical medical assessment tools for infants and children in a rehabilitation centre in Arusha, Tanzania, was identified.

Project Description

Located in Arusha, Tanzania, The Plaster House provides rehabilitative care to children with treatable disabilities receiving surgical treatments at local hospitals. Working in partnership with local and international surgeons, the programme provides care to approximately 700 children annually, with an average daily census of 160 children. Infants and children up to 18 years, typically stay at The Plaster House from 4 - 24 weeks before and after orthopaedic surgery, plastic surgery, neurological surgery, or general surgery. Common conditions treated include clubfoot, cleft lip and palate, skeletal fluorosis, spina bifida and hydrocephalus, and burn scar contracture releases; less common surgeries include treatment for osteomyelitis, enlarged adenoids/tonsils, and anorectal malformations. While

at The Plaster House, children participate in occupational therapy, educational and play interventions, regular medical check-ups, and nutritional eating. The majority of children come from low-income households in the regional catchment area of northern Tanzania.

In June 2020, The Plaster House and an interdisciplinary team of health sciences faculty at St. Catherine University (St. Kate's) in St. Paul, Minnesota, developed a collaborative partnership. The primary purpose of the partnership was to develop a programme evaluation plan and assessment tools for The Plaster House. Over 18 months, the team went through multiple iterations to develop process, outcome, and impact objectives for each of the programme goals. The purpose of this paper is to describe the process of medical assessment tool development and provide samples of the assessment tools. This tool was designed to measure the achievement of one specific programme goal: to provide high quality, efficient, and effective individualised therapeutic care for children with surgically treatable disabilities and their caregivers, throughout their stay at The Plaster House. The phases of the medical assessment tool development are described. First, background information was obtained for each treatable disability served. In the second phase, a clinical assessment tool designed to monitor progress during the child's stay was conceptualised. Ultimately, a medical assessment tool, which includes diagnosis-specific outcomes and questions related to quality of life, was developed from the progress assessment tool.

Objective

Given the paucity of existing assessment tools applicable to limited-resource settings, this article aimed to fill a gap by providing sample outcome measurements for post-operative rehabilitative paediatric care, in order to effectively collect monitoring and evaluation data.

METHOD

Study Design

This is a descriptive study detailing the development of medical assessment tools to collect data on newly established programme goals. It is part of an overall programme evaluation conducted through a collaborative community-academic partnership between July 2020 and January 2022. The staff and faculty involved in the evaluation met virtually, twice a month, to develop project objectives and

develop assessment tools. The Plaster House team primarily included three occupational therapists, two medical attendants and a social worker. The St. Kate's team included faculty with the following disciplinary training: physician assistant, nursing, occupational therapy (OT), physical therapy (PT), nutrition, social work and public health. The collective group across both institutions is referred to as the "evaluation team."

Over the first four months, the evaluation team facilitated an assets mapping process with The Plaster House. Primary programmatic goals were established during the development of a logic model, one in which the medical assessment tool was designed to measure the objectives.

Medical Assessment Tool - Phase 1: Background

The initial approach of the assessment tool development focused on eight care pathways for commonly treated conditions already in place at The Plaster House. These included post-surgical care plans for cleft lip and palate, spina bifida, skeletal fluorosis, osteomyelitis, burns, clubfoot/neglected clubfoot, and hydrocephalus. These established care pathways defined the monitoring and evaluation process by listing required action steps, assigning The Plaster House team members to those actions, and creating an overall timeline for the pathway. The evaluation team initially considered the utility of developing measures according to different disciplinary perspectives (e.g., OT, PT, nursing, nutrition), for a child admitted under each care pathway but determined it was not practical.

Medical Assessment Tool - Phase 2: Design

Given that the similarities were identified for all care pathways, the evaluation team began creating a "rounding" tool that was somewhat generic but could be easily adapted to each specific care pathway. The team developed a pilot outcome-based rounding tool beginning with one specific care pathway: spina bifida. The tool examined three categories of outcomes important for this population: skin integrity, activities of daily living (ADLs) and quality of life. These were designed to be brief touchpoints that were easy to conceptualise as "improving", "maintaining", or "declining" at three time points: immediately post-surgery, during the rehabilitation phase at The Plaster House, and following discharge. When used during the rehabilitation phase, the tool could serve as a clinical progress assessment or rounding tool. The initial tool created for children admitted on the spina bifida care pathway is shown in Figure 1. Ultimately,

The Plaster House team determined that while the tool measured the identified items for outcomes, it was too labour intensive for their staff-client ratio, and not practical for routine use.

Figure 1. Pilot outcome-based rounding tool created for children with spina bifida.

	Immediate (at intake)	Short-term (upon discharge)	Long-term (follow-up interview)
Skin integrity	Are there any acute signs of infection?	Are the client and Mother able to verbalize signs and symptoms of infection?	Is the client able to maintain skin integrity/ free from infection while performing everyday tasks?
	<input type="checkbox"/> Improving <input type="checkbox"/> Maintaining <input type="checkbox"/> Declining	<input type="checkbox"/> Improving <input type="checkbox"/> Maintaining <input type="checkbox"/> Declining	<input type="checkbox"/> Improving <input type="checkbox"/> Maintaining <input type="checkbox"/> Declining
Activities of daily living and functional mobility	Does the client attempt to engage in functional mobility and everyday tasks?	Does the client perform functional mobility and everyday tasks at an age appropriate level?	Is the client able to perform everyday tasks (age appropriate) while in their home?
	<input type="checkbox"/> Improving <input type="checkbox"/> Maintaining <input type="checkbox"/> Declining	<input type="checkbox"/> Improving <input type="checkbox"/> Maintaining <input type="checkbox"/> Declining	<input type="checkbox"/> Improving <input type="checkbox"/> Maintaining <input type="checkbox"/> Declining
Quality of Life	Client presents to be coping with transition to The Plaster House. Is the client demonstrating age appropriate play and interaction behaviors with peers and staff?	Does the client demonstrate psychosocial adjustment to increased function?	Demonstrate ability to advocate for needs/ wants
	<input type="checkbox"/> Improving <input type="checkbox"/> Maintaining <input type="checkbox"/> Declining	<input type="checkbox"/> Improving <input type="checkbox"/> Maintaining <input type="checkbox"/> Declining	<input type="checkbox"/> Improving <input type="checkbox"/> Maintaining <input type="checkbox"/> Declining

Medical Assessment Tool - Phase 3: Development

The final charge of the evaluation team was to create a medical assessment tool that included a single diagnosis-specific indicator for each care pathway and adaptable-to-age appropriate markers for progress. Even though the rounding tool conceptualised in Phase 2 for children with spina bifida was not practical, it served as a launching point for diagnosis-specific indicators in Phase 3. Instead of the original time points identified (post-surgery, during rehabilitation, and following discharge), the ideal assessment times were deemed to be intake and discharge, at minimum. The team reviewed international standards and peer reviewed literature to determine the most feasible and appropriate single indicator for positive change for each care pathway. Following consensus on indicators across all evaluation team members, The Plaster House team reviewed the chosen indicators to determine implementation feasibility and training needs for staff. The academic team created brief training materials and resources for these tools, and piloting began in January of 2022.

Data Collection

At this time, The Plaster House is using a free Electronic Health Record (EHR) system that has been adapted to their programme needs over the last two years. Ideally this medical assessment tool will be utilised through The Plaster House's EHR, simplifying the process for medical staff at The Plaster House. Given current challenges with the EHR software, the staff at The Plaster House are using Google Forms as an outside platform to collect data on client progress.

Ethics Approval

This study was approved by the St. Kate's Institutional Review Board #1547, St. Paul, 163 Minnesota, United States of America.

RESULTS

The medical assessment tool serves multiple purposes for the rehabilitation programme, including monitoring programme participants' progress, evaluating the effectiveness of current practices, and sharing data with stakeholders. It was essential to The Plaster House team that the medical assessment tool was easy to complete and export for analysis. The Plaster House will be utilising the final iteration of the medical assessment tool to track the outcomes of post-operative participants in the rehabilitation programme. The tool is primarily completed by occupational therapists, social workers, and medical professionals. Housed in Google Forms, the full medical assessment tool tracks age-appropriate markers and diagnosis-specific data to monitor the recovery and progress of children in the care of The Plaster House by completing the assessment at intake and discharge.

The medical assessment tool is best understood by dividing it into three sections. The first section collects demographic and background information. Demographic information includes name, medical record number, sex, tribe, and age. Background information includes a question related to the child's presenting diagnosis and nutritional status; a z-score (10 years of age) is collected, depending on the client's age. The second section of the medical assessment tool is diagnosis-specific. Each condition or care pathway has one uniquely defined indicator to measure progress. Commonly used measurements are utilised for a number of the diagnoses addressed in the second section of the medical assessment tool. For example, for burn scar contractures, the tool prompts the medical team to gather range of motion measurements at the involved joint, using a goniometer. These

measurements are recorded in degrees. For a child with clubfoot, the child's Pirani score is documented at diagnosis. The Pirani scoring system is frequently used to categorise and monitor progress of treatment for clubfoot (Mejabi et al, 2016). For children who present with hydrocephalus, the tool prompts the medical team to record the child's head circumference in centimetres. Wound measurements are gathered for children with osteomyelitis. These measurements are documented using length, width, and depth in centimetres.

When commonly used measurements or assessments failed to meet the needs of The Plaster House, the evaluation team designed unique questions. For example, if a child presents with a diagnosis of cleft lip, cleft palate, or palate fistula, The Plaster House team is prompted to assess the child's ability to self-feed at an age-appropriate level. The rating scale ranges from "no support" (eating and drinking well without adaptive equipment) to "intense support" (requires more than average help from the medical team, house mothers, or hospitalisation). Rankings in between include "mild support" (eating and drinking well with adaptive equipment and is progressing well) and "moderate support" (difficulty eating or drinking with adaptive equipment or not progressing well) as shown in Figure 2.

Figure 2. A screenshot of a portion of the Cleft lip/palate/fistula tool in Google Forms.

Cleft lip/cleft palate/palate fistula Medical Tool Score

Ease of feeding scale/support of feeding

Required for age appropriate support: *

- No support (eating and drinking well with no adaptive equipment)
- Mild support (eating and drinking well with adaptive equipment and is progressing well)
- Moderate support (difficulty eating or drinking with adaptive equipment OR not progressing well)
- Intense support (requires more than average help from med team, house mothers, or hospitalization)
- Other: _____

The Plaster House staff document gait distance and level of assistance needed for children who present with skeletal fluorosis. The medical assessment tool contains fields to record the general distance the child can walk, with options including “household distances” and “community distances”. The term “community distances” is defined by The Plaster House staff as being able to walk to and from the market, school, and church. The level of assistance required to complete functional mobility is documented using a scale that ranges from “No help, keeps up with peers, and can walk community distances” (Example: can walk to school without difficulty) to “No help but slower pace and/or cannot keep up with peers, shows signs of fatigue. It is difficult for the client to walk community distances” (Example: can walk to school, but it is difficult); and “Needs help. Cannot walk community distances. No participation in everyday activities. Can do home chores but not the outside chores” (Example: cannot walk to school, cannot herd animals, can walk within the home).

Lastly, for a child with spina bifida, bladder and bowel continence questions are utilised. The tool asks if the child is continent of bladder and bowel. If the child is incontinent of bladder or bowel, the follow-up question asks who manages the bladder and/or bowel incontinence. Answer options include “child managed”, “parent managed”, and “not managed”. The current version of the medical assessment tool is shown in Figure 3.

Figure 3. The final Medical Assessment Tool collecting the child's demographic information, diagnosis-specific indicators, and age-appropriate interactions.

<p>Section One:</p> <p>Patient Name: Plaster House Number:</p> <p>Is this assessment being conducted at:</p> <ul style="list-style-type: none"> • Intake • Discharge • Other: _____ <p>Gender: Tribe: Age:</p> <p>Malnourishment Assessment (under the age of 10 years): What is the patient's z-score?</p> <p>Malnourishment Assessment (over the age of 10 years): What is the patient's BMI?</p> <p>Patient Diagnosis:</p> <ul style="list-style-type: none"> • Burn scar contracture • Cleft lip/ cleft palate/ palate fistula • Clubfoot/neglected clubfoot • Skeletal Fluorosis • Hydrocephalus • Osteomyelitis • Spina bifida 	<p>Club Foot Medical Tool Score: Pirani Score:</p> <p>Fluorosis Medical Tool Score: Can the child walk household distances? Can the child walk community distances?</p> <p>Level of independence:</p> <ul style="list-style-type: none"> • No help/keeps up with peers. Can walk community distances. (Example: can walk to school without difficulty) • No help but slower pace/ cannot keep up with peers. Shows signs of fatigue. It is difficult for the client to walk community distances. (Example: can walk to school, but it is difficult) • Needs help. Cannot walk community distances. No participation in everyday activities. Can do home chores but not the outside chores. (Select this option if the client needs help, regardless of how much help is needed) • Other: <p>Hydrocephalus Medical Tool Score: Head circumference in centimeters:</p> <p>Osteomyelitis Medical Tool Score: Wound dimensions (Length x Width x Depth) in centimeters:</p> <p>Spina Bifida Medical Tool Score: Is the client continent of bladder?</p> <ul style="list-style-type: none"> ○ Yes ○ No
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Section Two:**Burn Medical Tool Score:**

Where was the measurement(s) taken? What was the measurement(s) in degrees?

- Wrist flexion/ extension
 - Range of Motion- Goniometer measurements:
- MCP and IP flexion/ extension
 - Range of Motion- Goniometer measurements:
- Elbow flexion/ extension
 - Range of Motion- Goniometer measurements:
- Shoulder abduction/ adduction
 - Range of Motion- Goniometer measurements:
- Shoulder flexion/ extension
 - Range of Motion- Goniometer measurements:
- Hip flexion/ extension
 - Range of Motion- Goniometer measurements:
- Knee flexion/ extension
 - Range of Motion- Goniometer measurements:
- Ankle flexion/ extension
 - Range of Motion- Goniometer measurements:

• Other: _____
Range of Motion- Goniometer measurements:

Cleft lip/ Cleft palate/ Palate fistula Tool Score:

Level of support required for age-appropriate support:

- No support (eating and drinking well with no adaptive equipment)
- Mild support (eating and drinking well with adaptive equipment and is progressing well)
- Moderate support (difficulty eating or drinking with adaptive equipment OR not progressing well)
- Intense support (requires more than average help from the medical team, house mothers, or hospitalization)
- Other: _____

Is bladder incontinence:

- Child managed
- Parent managed
- Not managed
- Other:

Is the client continent of bowel?

- Yes
- No

Is bowel incontinence:

- Child managed
- Parent managed
- Not managed
- Other:

Section Three:**Age-Appropriate Interactions**

Is the client demonstrating age-appropriate:

- Everyday tasks
 - Yes
 - No
- Play
 - Yes
 - No
- Social interaction with peers and staff
 - Yes
 - No

The third and final section of the medical assessment tool includes questions related to typical development to incorporate a biophysical model of assessment (World Health Organisation, 2002) that is completed for all children. The questions ask the medical team member to evaluate the child's ability to perform at an age-appropriate level in the areas of everyday tasks, such as ADLs, play, and social interaction.

DISCUSSION

Currently, there are few examples in the literature on outcome measurement tools for post-surgical paediatric care in low-resource settings. The literature focuses primarily on client safety outcomes or quality of care centred around the time in the hospital (Butler, 2016; Lelli Chiesa et al, 2020; Philipo et al, 2020) or preparing for surgery (de Oliveira Pires et al, 2013), thus overlooking post-operative rehabilitation (Berry et al, 2019). It is noteworthy that there are diligent efforts to address client safety by the WHO in creating Global Patient Safety Action Plan 2021-2030, with a vision of prioritising safe and respectful care (World Health Organisation, 2021). A focus on translating evidence into actionable and measurable improvement outcomes for clients is presented by the WHO; however, there is no explicit statement for each time point of perioperative care.

One of the seven strategic objectives of the Global Patient Safety Action Plan is to, “Develop and sustain multisectoral and multinational synergy, partnership and solidarity to improve client safety and quality of care”, in which monitoring and reporting is at the forefront (World Health Organisation, 2021). Luan, Mghase, Meyers and Chang (2021) note the importance of monitoring and evaluation in providing quality perioperative care. This medical assessment tool may begin to fill the gap as one example of an effective and efficient monitoring and evaluation tool for outcome data in the post-operative period.

In the development of the tool, successes and challenges of working with an international organisation in a low-resource setting arose. A strength of this project was the development of a medical assessment tool that was built as a response to a programme logic model, with the main outcomes focused on activities and outputs directed towards individualised, therapeutic care in all aspects of the programme (Field et al, 2018). Moreover, The Plaster House staff was directly involved in the tool development, as feedback on the plausibility of the tool was critical. Regular monitoring and communication across the evaluation team was required to ensure early identification of issues with the tool, resources available to adequately assess the outcomes for each child, and determine EHR capacity.

As a result of continuous communication, the medical assessment tool evolved through multiple iterations over 18 months. An example of this feedback loop is presented in the drafting of the tool. The second phase of the tool shown in Figure 1 was presented to the evaluation team and was deemed to be too laborious in a medical rounding scenario, resulting in the evaluation team bringing the idea forward for a single measurement outcome. Although The Plaster House was not able to use the design phase tool, it may be appropriate for use by other organisations seeking a more generalised tool for rounding.

The evaluation team observed that in the United States of America it is common to use complex and didactic processes, especially with regard to assessment in medical practice. One lesson learned is that elaborate assessment tools were not plausible for The Plaster House and perhaps are overly complex in U.S. settings as well. Studies have shown that simple, utilitarian tools such as checklists can improve quality of care and save lives (Gawande, 2011). Other research in Tanzania has focused on developing simple tools to monitor client outcomes post-operation. Abraham, Kahinga, Mapondella, Massawe, and Ntunaguzi (2020) documented the use of two post-operative outcomes, haemorrhage and infection rate, to measure success in adenotonsillectomy in Tanzanian hospitals. It was not

possible to evaluate data from programme activities already occurring at The Plaster House (Field et al, 2018), as minimal data was being collected. Therefore, in developing the medical assessment tool, the evaluation team worked together to identify one disease-specific indicator to support the general developmental progress indicators. These outcomes were chosen as evidence-based measures that would be easy to collect and reliable if different team members at The Plaster House collected the measurement, for higher inter-rater reliability. Simple and relevant measurements are necessary to minimise staff burden. The additional data collected will allow The Plaster House to collect baseline information to report to stakeholders.

Limitations

The limitations to this work are largely attributed to the St. Kate's team's inability to conduct an on-site visit due to the pandemic. This made it difficult to determine the use of the tool in practice. In this scenario, the faculty team relied heavily on effective communication with The Plaster House team to sufficiently relay challenges and successes with the tool. Additionally, not all NGOs have the staffing capabilities or EHRs to support data collection in the capacity that is being requested (Bach-Mortensen & Montgomery, 2018; Field et al, 2018; Luan et al, 2021). The EHR utilised in this case does not have the capacity to print reports, therefore the assessment tool had to be housed elsewhere, creating a barrier to ease of implementation and accessibility. Finally, the medical assessment tool has not been validated; instead it is supported by evidence-based progress indicators.

CONCLUSION

The medical assessment tool presented in this paper was designed for a unique model that The Plaster House is utilising in its post-surgical rehabilitation centre to advance monitoring and evaluation outcomes in children. The tool is intended to bring more effective and practical monitoring and evaluation of paediatric outcomes in low-resource settings such as Tanzania (Luan et al, 2021). It is specifically designed for monitoring children post-surgery for treatable disabilities such as burn contracture release, cleft lip/cleft palate, clubfoot, hydrocephalus, osteomyelitis, skeletal fluorosis, or spina bifida. Built from the framework of a logic model, the medical assessment tool focuses on the specific needs of The Plaster House in measuring their goal, "To provide high quality, efficient, and effective individualised therapeutic care for children with treatable disabilities

and their caregivers throughout their stay at The Plaster House.” Using a logic model to improve health service outcomes is consistent with recommendations from parallel work (Field et al, 2018).

Monitoring and evaluation has proved to be a challenge where resources are limited (Luan et al, 2021). This could be attributed to lack of financial resources, technical capability and evaluation literacy, and/or challenges in identifying relevant evaluation systems and outcome indicators (Bach-Mortensen & Montgomery, 2018; Luan et al, 2021). This project has reiterated that The Plaster House was not an exception, as employee capacity and EHR difficulties present as barriers to monitoring and evaluation. While piloting is in process, Bach-Mortensen and Montgomery’s key factors to promote monitoring and evaluation such as getting appropriate support, promoting a culture that supports evaluation, and providing motivation to be accountable to stakeholders (Bach-Mortensen & Montgomery, 2018) will be utilised to ensure the success of the tool. Moreover, by collecting measures during a rehabilitative stay, it allows for two time points to be measured and reduced loss to follow-up (Hendriks et al, 2019; Luan et al, 2021).

In conclusion, the medical assessment tool has the potential to capture practical outcome measurements for children with surgically treatable disabilities post-operation, during rehabilitative care, in low-resource settings.

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The Experiences of Public Transport Drivers with People with Disability in the City of Tshwane, South Africa

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ABSTRACT

Purpose: *Public transport drivers are an intermediary between transport infrastructure and passengers with disability. The purpose of this study was to understand the perspectives of public transport drivers on their encounters with passengers with disability, and the impact this has on public transport inaccessibility.*

Method: *A qualitative research approach was applied. A semi-structured interview guide was utilised to collect data from public transport drivers. Thematic analysis was used to analyse data and an inductive approach was followed to allow data to determine themes.*

Results: *The study found that public transport drivers operate under challenging conditions. The drivers' main issues and challenges are lack of training and knowledge on disability, negative attitudes displayed by passengers, and having to satisfy conflicting demands from both employers and passengers with disability. The conflicting demands are intensified by the lack of universally designed vehicles and infrastructure.*

Conclusion: *The actions of transport providers contribute to transport inaccessibility. The identification of issues and drivers' concerns in this study could help to enhance driver training, improve transport services and enrich inputs into public transport policies.*

Key words: *passengers with disability, public transport, transport barriers, public transport drivers, people with disability, attitudes*

INTRODUCTION

Accessible public transport enables the socio-economic participation of people with disability (Park & Chowdhury, 2018). The National Household Travel

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Survey (NHTS) 2020 of South Africa reported that public transport is the main mode used by most households (Stats SA, 2021). The three main modes which constitute the public transport system in the City of Tshwane are mini-bus taxis, buses and trains, with mini-bus taxis as the most used and most available mode (Stats SA, 2021). However, many people with disability experience transport inequalities. Access to public transport is restricted by various factors which can be classified as structural, service quality, socio-demographic, institutional or psychosocial barriers (Bjerkan & Ovstedal, 2018; Oksenholt & Aarhaug, 2018; Park & Chowdhury, 2018; Kett, Cole & Turner, 2020).

Service delivery for passengers with disability who use public transport can be influenced by drivers' knowledge of and attitudes towards passengers with disability (Fast, 2019). Drivers' encounters with passengers with disability should be understood and their feedback incorporated in transport planning to provide transport services that meet the needs of passengers with disability.

This study focused on only three groups of people with disability – those with mobility, visual and hearing disability, as they are among the groups that face severe transport problems compared to other groups with disability (Bezyak et al, 2020). Mobility disability is a type of disability that affects the movement of the body (Bekiaris et al, 2018). To improve mobility, people with mobility disability can use mobility aids such as “wheelchairs, walking sticks, or crutches” (Vanderschuren & Nnene, 2021). According to Census 2011, in South Africa there are approximately 2.6% of people with mobility disability (Stats SA, 2014). Visual disability refers to the degree of sight loss, ranging from partial blindness to total blindness (Bekiaris et al, 2018). The sense of sight enables vision, giving the individual the ability to distinguish light and darkness, motions, colours, shapes and position (Ružičková, 2016). Depending on the degree of disability, some people with visual disability find it difficult to see images (Bekiaris et al, 2018). Worldwide, about one billion people are living with some form of visual disability (WHO, 2018), while in South Africa, there are approximately 900, 000 people with visual disability of some sort (Stats SA, 2016). People with hearing disability find it difficult to hear sounds or speech in the environment (Bekiaris et al, 2018). Hearing loss results in a loss of auditory information (Thorslund, Peter, Lyxell & Lidestam, 2013). According to the 2011 Census data, approximately 3.3% of the South African population has some form of hearing disability (Stats SA, 2016).

Public Transport Drivers

Public transport drivers play a critical role in public transport services (Brunoro, Sznelwar, Bolis & Abrahao, 2015; Fast, 2019; Abraham et al, 2021). Drivers may serve as part of a support system to people with disability in accessing public transport, enabling them to overcome existing barriers (Tillmann, Haveman, Stöppler, Kvas & Monninger, 2013; Oksenholt & Aarhaug, 2018). However, the literature reveals that some drivers' attitudes and behaviour clearly show a lack of understanding of the issues faced by people with disability. The drivers' attitudes and behaviour are widely documented as one of the most critical barriers to access public transport for people with disability (Tillmann et al, 2013; Bezyak et al, 2017; Oksenholt & Aarhaug, 2018; Park & Chowdhury, 2018; Fast, 2019; Owusu-Ansah, Baisie & Oduro-Ofori, 2019). Negative attitudes are classified as psychosocial barriers in literature (Ahmad, 2015; Park & Chowdhury, 2018).

It is argued that the mere provision of universally designed vehicles is not sufficient to enable accessible transport (Tillman et al, 2013). To serve passengers with disability, drivers should be aware of the needs and rights of passengers with disability (Fast, 2019). Many public transport drivers are not trained and are unaware of the transport needs of people with disability, which creates significant transport barriers for people (Bezyak et al, 2017). However, some of the drivers' actions may be unintentional, especially towards people with disability that is not obvious. For example, a driver might not be aware that a person needs help to board the vehicle unless informed (Oksenholt & Aarhaug, 2018).

It is also important to understand the job demands of public transport drivers, which may affect service quality and accessibility. A driver's job is not only to drive but also to interact with passengers and deal with different kinds of situations during the transportation of passengers (Chaparro, Galilea, Muñoz & Poblete, 2020). Drivers have to satisfy conflicting demands of the employer and the passenger, as well as observe traffic rules and regulations, which may intensify their stress (Chen & Hsu, 2020).

Drivers interact with a diverse population of passengers with different needs (Brunoro et al, 2015); as such challenges are inevitable and, in some cases, drivers may not be able to meet the needs of all passengers. Stjernborg (2019) found that stressed drivers often pose transport barriers and create feelings of insecurity in people with disability. In South Africa, mini-bus taxi drivers work with daily revenue targets required by the taxi owners (Kett et al, 2020); given this scenario,

these drivers are more likely to work under pressure to meet daily revenue targets. Similarly, bus drivers work with a timetable and constantly deal with pressure to meet the schedule (Brunoro et al, 2015).

Understanding and acknowledging the importance of drivers can influence the quality of transport services offered (Chaparro et al, 2020) and improve the travel experiences of people with disability. Although many studies have considered barriers in accessing public transport from the perspective of people with disability (Park & Chowdhury, 2018; Stjernborg, 2019; Velho, 2019), little research has focused on transport barriers from the perspective of public transport drivers. The relationship between drivers and passengers with disability requires an understanding of the issues that drivers face in the course of performing their duties. To improve public transport services, drivers' encounters with passengers with disability should be understood, addressed and integrated into city policies.

Objective

This study aims to understand the perspective of public transport drivers on their encounters with passengers with disability, and the impact this has on public transport inaccessibility. To this end, three objectives were formulated:

- 1) To establish challenges encountered by drivers in providing transport services to the passengers with disability.
- 2) To explore the attitudes of drivers towards passengers with disability.
- 3) To determine whether drivers are aware of the needs of passengers with disability.

METHOD

Study Setting

The study area was the City of Tshwane, which is located in the Gauteng province of South Africa. It was chosen for the study partly due to the increase in the prevalence of people living with some form of disability between 2011 and 2016 (Stats SA, 2018). In the City of Tshwane, the main modes of public transport are mini-bus taxis, buses and trains (Stats SA, 2021). It is inevitable that many people with disability will experience problems in accessing public transport, given the lack of universally accessible transport infrastructure and services in South

Africa at large (Lister & Dhunpath, 2016; Morta-Andrews, 2018; Rivasplata & Le Roux, 2018).

Study Design

The research followed a constructivism research philosophy. The understanding or meaning of phenomena, formed through participants and their subjective views, make up constructivism research philosophy (Creswell & Plano Clark, 2018). A qualitative research method was considered to be the preferred method to collect data from drivers to add depth to reasons underlying public transport inaccessibility.

Study Sample

The non-probability purposive sampling method was used, meaning that “researchers intentionally select (or recruit) participants who have experienced the central phenomenon or key concept being explored in the study” (Creswell & Plano Clark, 2018). Drivers who were available and willing to participate in the study were intentionally recruited to provide valuable information. Table 1 shows the demographics of drivers who participated in the study.

Table 1: Demographics of Drivers

Name	Age	Gender	Type of Driver
Driver 1	50	Male	Bus
Driver 2	47	Male	Bus
Driver 3	61	Male	Bus
Driver 4	41	Male	Mini-bus taxi
Driver 5	29	Male	Mini-bus taxi
Driver 6	36	Male	Mini-bus taxi
Driver 7	45	Male	Mini-bus taxi
Driver 8	38	Male	Mini-bus taxi
Driver 9	47	Male	Mini-bus taxi
Driver 10	42	Male	Bus

This study only focused on three groups of people with disability – those with mobility, visual and hearing disability, as they are among the groups that face severe transport problems compared to other groups with disability (Bezyak et al, 2020).

Data Collection

A semi-structured interview guide was utilised to collect data from public transport drivers. The interviews for drivers were carried out at mini-bus taxi ranks and bus stations in Pretoria during off-peak hours, from Monday to Friday, in May 2021. The process of data collection would start by the researcher introducing herself, then informing potential participants about the study and asking whether they were interested in participating. They were informed that participating in the study was voluntary and they could withdraw at any time and without giving any reasons. They were assured that their responses would be kept anonymous and confidential. All those who agreed to participate gave their consent orally and were thanked the same way. No incentives were offered for their participation.

Data Analysis

Data was mainly captured in writing, as many drivers were not willing to have their responses audio-recorded. MAXQDA 2020 software for quantitative and qualitative data analysis was used. An inductive approach was followed so as to allow data to determine themes. Braun and Clarke (2006) define inductive analysis as “a process of coding the data without trying to fit it into a pre-existing coding frame, or the researcher’s analytic preconceptions”. According to Bryman and Bell (2017), thematic analysis is most appropriate for studies which consider people’s opinions, experiences, knowledge or values. The current study conducted thematic analysis using the process developed by Braun and Clarke (2006): (1) familiarisation with the data, (2) coding, (3) generation of themes, (4) reviewing of themes, (5) defining and naming themes, and (6) writing up the narrative of the data.

Ethical Considerations

Ethical approval for the study was granted by the Department of Transport and Supply Chain Management Ethics Committee of the University of Johannesburg. This research adhered to all the ethical research requirements as per the University’s policy on ethical clearance certification. Most drivers were not willing to give formal consent (signatures); therefore, an informal consent form was used. All the drivers who agreed to participate gave verbal consent. The researcher also explained to the participants that there were no correct answers and their responses would be kept anonymous and confidential.

RESULTS

The six themes derived from the analysis are as follows: (1) organisational procedures; (2) travel assistance; (3) attitudes of passengers with disability towards drivers; (4) challenges experienced by drivers; (5) attitudes of drivers towards passengers with disability; and (6) training and awareness.

Theme 1: Organisational Policies and Procedures

Organisational policies and procedures guide the work that is carried out by drivers. Restrictive policies can create unintentional barriers for passengers with disability. In this study, although written organisational policies and procedures could not be obtained, given below are some of the issues that emerged from discussions with drivers.

“We are not allowed to help people who have disability. But some passengers, who are willing to help, do that. People who use wheelchairs are at the mercy of other passengers” (Driver 3).

This response suggests that passengers who use wheelchairs need to travel with their assistants. Another participant mentioned that drivers are not allowed to help passengers with disability, especially those who use wheelchairs.

“My company policy is that a person with a disability should have a travel assistant who will help him or her (those in wheelchairs). Drivers are not allowed to help them because sometimes you try to help them and they fall, it will be your fault. When they fall, they will claim money from the company for compensation” (Driver 1).

Most excerpts illustrated that many drivers could not help passengers in need of assistance in boarding and alighting because many transport providers are not prepared to take responsibility in the event that a driver gets injured or injures a passenger.

Theme 2: Travel Assistance

Depending on the type of disability, some passengers with disability need to access transport with travel assistants. Some of the issues discussed by interviewees were about travel assistance.

“... they are unable to help themselves, they need my help, whereas during peak hours it's difficult to help them because other passengers are going to work, and they are not allowed to board the bus” (Driver 4).

The response from Driver 4 conveys his perception that the needs of other passengers going to work are more important than those of passengers with disability. In addition, he seems to think that passengers with disability do not work. The response of Driver 4 also suggests that perhaps passengers who need travel assistance are left behind at bus stops.

Another driver mentioned that passengers with disability should be accompanied by a travel assistant.

“Basically, a person with a disability should have someone to help them” (Driver 1).

The responses of Drivers 2 and 3 mention the driver’s role.

“... normally, my job is to drive, we do not help people with disabilities. But sometimes other passengers help them to get in” (Driver 2).

“...no, we are not allowed, some passengers who are willing to help do that” (Driver 3).

These two responses suggest that passengers with disability who need travel assistance depend on other passengers in the event that they are travelling without helpers.

Theme 3: Attitudes of Passengers with Disability towards Drivers

One interviewee gave an account of how some passengers with disability react to drivers.

“I feel pity for them. But many are rude and arrogant. They should accept their condition first and maybe they feel let down by other previous drivers they had bad experiences with. If one driver treated them bad, they think that all the drivers are all the same. When it comes to people who have disability, they are short-tempered, aggressive and rude. Even when the driver comes out of the seat to help them in, they don’t want” (Driver 1).

This response reflects that passengers with disability are probably not happy with drivers. Driver 1 perceives that passengers with disability have a preconception that all drivers do not treat passengers with disability well.

Theme 4: Challenges Experienced by Drivers

Drivers deal with different groups of passengers, and challenges would be inevitable. While some challenges are beyond the driver’s control, others can be avoided or managed.

“The only challenge is that you have to drop them exactly where they are going. You cannot transfer them into another taxi, because it’s hard for them to get into a taxi and then get out” (Driver 4).

This response reflects on the inaccessibility of public vehicles to some passengers with disability. One of the challenges is that mini-bus taxis are not designed to accommodate passengers with disability, especially those who use wheelchairs. Some drivers are not willing to provide transport services to people in wheelchairs.

“Loading a person using a wheelchair and the wheelchair takes too much time, so the company does not want us to spend so much time at bus stops” (Driver 2).

Driver 2 suggests that the vehicles do not have the necessary equipment to assist in the boarding and alighting of passengers who use wheelchairs. Without appropriate infrastructure, it could be difficult for drivers to assist passengers who use a wheelchair to get in and out of vehicles. Similarly, another driver mentioned that it is time-consuming to help passengers who use wheelchairs.

“During peak hours I do not carry people with wheelchairs because it takes too much time to load a wheelchair and put the passenger inside the vehicle. I will not make a lot of money if I carry people with wheelchairs and miss my target for the day” (Driver 6).

Driver 9 mentioned how passengers who use wheelchairs may impact on the daily revenue targets.

“The taxi owner does have rules on carrying passengers with disabilities. But I work with daily targets, so if I carry a person in a wheelchair, they will occupy a paying seat on vehicle. I can only carry a person in a wheelchair during off peak” (Driver 9).

Drivers are concerned about the extra time required to stop and pick up a person in a wheelchair. Many people in wheelchairs take a lot of time to board transport, which may be unfair to other people with disability. Passengers with visual and hearing disability may not need strenuous physical assistance to board and alight from vehicles. Although passengers with visual disability need guidance, drivers may find it less strenuous to help them.

Theme 5: Attitudes of Drivers towards Passengers with Disability

The study found that some drivers empathise with passengers with disability and are aware that they should be treated with respect and dignity. However, some of the actions of drivers do not necessarily match the sentiments expressed during the interviews.

“You know, a person is a person, people who have disability are also human beings; we must treat them properly. I have humility...”(Driver 8).

“I think they also deserve to be treated like everybody, they need that special treatment” (Driver 10).

One driver was of the opinion that people with disability are not problematic passengers most of the time.

“Most of the time they are not difficult” (Driver 4).

Some drivers understand the frustrations of passengers with disability to some extent.

“Sometimes when you are heartbroken or coming from work, someone has treated you badly, so when coming to the taxi you continue being angry at other people, your mind is still thinking about what happened” (Driver 7).

Some drivers help passengers with disability, while some others are not helpful.

“We are able to help people in wheelchairs as we do have time to do it, unlike other taxis which pick and drop passengers; they would be chasing after passengers so they won’t stop for people in wheelchairs or who need help to get into the taxi” (Driver 5).

Drivers need to be supported so that they can better understand the difficulties faced by passengers with disability and provide satisfactory and improved services.

Theme 6: Training and Awareness

The discussions with the drivers brought out some of the key issues concerning training and awareness.

“Our company does not train drivers on how to handle passengers with disabilities, except a few drivers who drive dedicated buses which carry passengers with disabilities” (Driver 1).

Most drivers reported that they are not trained to handle passengers and are unaware of some of the needs of passengers with disability.

“I have never been trained to handle passengers with disabilities” (Driver 4).

“Where I was working previously, we did some training but at this company I am now at, they do not train drivers on how to handle people with disabilities” (Driver 10).

DISCUSSION

The study focussed on passengers with mobility, hearing and visual disability. However, the results revealed that critical issues mainly concern passengers with mobility disability, especially those who use wheelchairs. To confirm that the interviewees had understood the questions and the interviewer had understood the answers, eight follow-up telephone interviews were conducted to clarify further information pertaining to passengers with vision and hearing disability. The drivers' responses could not give conclusive evidence on the challenges that are faced when providing services to passengers with visual and hearing disability. There are two possible reasons for this:

- 1) Passengers with visual and hearing disability generally do not encounter many difficulties in boarding and alighting from vehicles. Compared to passengers with mobility disability, it seems easier to help passengers with visual disability as they only require guidance. Passengers with mobility disability may require the physical assistance of a driver or a travel assistant in boarding and alighting from vehicles.
- 2) Drivers do not see people with hearing and vision disability as passengers needing help. As such, this may indicate a lack of understanding of the needs of different groups of passengers with disability.

Organisational Policies and Procedures

Some of the findings on organisational policies and procedures are in line with research done in Kumasi, Ghana, which elaborated that bus drivers seldom stop for a person in a wheelchair as they consider it time-consuming (Owusu-Ansah et al, 2019). Organisational policies and procedures which do not allow drivers to carry passengers with disability are discriminatory, yet access to transport should be a right for everyone (Lucas, 2011; Cepeda, Galilea & Raveau, 2018). In

the case of South Africa, transport is not acknowledged as a basic human right (Lucas, 2011). This is also common in other developing countries (Cepeda et al, 2018; Kett et al, 2020). There is no explicit right to transport in the Constitution of the Republic of South Africa (1996). Although some policies and procedures seem unfair and harsh, some could be designed to protect the drivers.

Unlike passengers with visual and hearing disability, there is a risk that a driver could hurt himself/herself while lifting a wheelchair or assisting a passenger to board or alight from the vehicle, as well as hurting the passenger. However, there are insurance policies which cover passenger liability and public liability. In South Africa, transport companies should also be registered in terms of the Compensation for Occupational Injuries and Diseases Act 130 of 1993 (COIDA) to cover the driver in case of unexpected events. If the transport companies do not cover themselves against unforeseen incidents, they may face lawsuits if a passenger is hurt or injured.

Travel Assistance

Different groups of people with disability require different forms of assistance as well; there are unique needs within the group itself (Park & Chowdhury, 2018). The findings in this study suggest that passengers who use wheelchairs require assistance in boarding and disembarking from vehicles and there is a need to travel with a travel assistant. As mentioned, passengers with hearing disability generally do not need physical assistance to get into a vehicle, but a person in a wheelchair usually needs physical help to get into and out of a vehicle. Although passengers with hearing disability can travel independently, assistance may be needed to communicate destinations (Green, Mophosho & Khoza-Shangase, 2015), while passengers with visual disability may need help in navigating spaces (Oksenholt & Aarhaug, 2018). People with hearing disability may avoid asking for assistance because of communication difficulties and the stigma associated with the disability (Green et al, 2015).

Due to lack of accessible transport infrastructure in the City of Tshwane, travel assistants play a vital role for passengers with disability, especially for those who cannot travel independently and those who use wheelchairs. In some cases it is beyond drivers to assist passengers with disability, while in other cases drivers are not willing to help. Perhaps the situation would be better if the existing transport infrastructure in the city was universally accessible. However, the literature portrays a different picture. Research done in New Zealand reveals that

despite the availability of universally accessible transport infrastructure drivers can be insensitive to the needs of people with disability (Park & Chowdhury, 2018). Other developed countries such as the UK and Sweden with universally accessible infrastructure also have these problems (Stjernborg, 2019; Velho, 2019).

Attitudes of Passengers with Disability towards Drivers

Previous research reveals that many drivers have negative attitudes towards people with disability (Ipingbemi, 2015; Bombom & Abdullahi, 2016; Abraham et al, 2021). However, there is little research reflecting the attitudes of passengers with disability towards drivers. The findings suggest that drivers and passengers with disability often struggle to communicate effectively. There are various reasons why passengers with disability might have negative attitudes towards drivers; for example, unsatisfactory services, previous bad treatment from drivers, prejudice and lack of training of drivers. Anger displayed by passengers with disability could be a way of communicating that they are receiving bad treatment (Ching & Chan, 2020). It could be argued that respect should be mutual; therefore, passengers with disability and drivers should respect each other. According to the Department of Transport (2020), to be treated with dignity and respect, it is essential for people with disability to show respect to drivers. However, some situations are aggravated by lack of or inadequate driver training.

Challenges Experienced by Drivers

The findings in this study indicate that drivers find it time-consuming to assist passengers who use wheelchairs. These findings are consistent with the findings from research done in Ghana by Owusu-Ansah et al (2019). Drivers are concerned about the time they waste when they stop to pick up a person in a wheelchair. Many passengers who use wheelchairs take more time waiting to board transport which may be unfair to passengers with disability. Lister and Dhunpath (2016) found that passengers who use wheelchairs typically spend about two hours waiting for transport. Passengers with visual and hearing disability are not significantly affected since they do not need strenuous physical assistance to board and alight from vehicles. Passengers with visual disability need guidance which may seem less strenuous to drivers.

Attitudes of Drivers towards Passengers with Disability

It was found that some drivers help passengers with disability while some are not helpful. The findings also reveal that there is lack of infrastructure for boarding

and disembarking which makes it difficult for drivers to assist passengers with mobility disability. To some extent, some drivers understand the frustrations of passengers with disability.

Training and Awareness

The study findings reveal lack of awareness and knowledge of disability among drivers in the City of Tshwane. Training of transport personnel on disability needs may increase drivers' sensitivity to passengers with disability and improve quality of service. According to the UN Convention on the Rights of Persons with Disabilities (UNCRPD, 2006), Article 4, governments have a responsibility "to promote the training of professionals and staff working with persons with disabilities in the rights recognised in the present Convention so as to better provide the assistance and services guaranteed by those rights".

Lack of training for drivers is not only found in developing countries but also in developed countries such as the US (Bezyak et al, 2017). It is a common problem across cities in different countries. Fast (2019) points out that difficulties arise when drivers do not have social interacting skills. In addition, Fast (2019) emphasises that social interacting skills are more important than other skills or knowledge.

The drivers in the City of Tshwane did not seem to understand the issues faced by passengers with disability, thereby contributing to the creation of barriers in accessing public transport. According to Park and Chowdhury (2018), "well-trained drivers can help people with disability feel more confident to use public transport". Without proper training, there is also a high risk of drivers hurting passengers with disability, either unintentionally or deliberately. In South Africa, the skills development and training of drivers is one of the challenges associated with the mini-bus industry (Mhlanga, 2017).

Limitations

A small sample was used to gather data on the encounters between drivers and passengers with disability. Generalisable conclusions could therefore not be drawn from the analysed data. The lack of generalisability is acknowledged as a limitation of this study and future research may address this issue by using probability sampling method and larger samples.

The study focus was on drivers of buses and mini-bus taxis, yet there are also drivers for other modes of transport services, for example, Uber drivers and

metered taxi drivers. Their encounters with passengers with disability could be equally important. Therefore, future studies could include drivers for different modes of transport that provide services to people with disability.

Implications

Many studies on disability and transport barriers have only focused on the perspectives of passengers with disability. This study creates a unique perspective by also considering the perspectives of the drivers who operate the services on the ground and are therefore able to describe the day-to-day problems faced in the course of their work, bridging the gap between passengers with disability and managers of the transport service. Based on the finding that most drivers are not trained to handle passengers with disability, training of transport personnel should be made a priority. Disability awareness among transport providers and their drivers may change their perceptions of passengers with disability. Transport issues and drivers' concerns established in this study could help to enhance driver training, improve transport services and enrich inputs into public transport policies.

CONCLUSION

This research is one of the few studies focusing on the encounters of public transport drivers with passengers with disability. The relationship between drivers and passengers with disability is crucial as it contributes to the travel experience of passengers with disability. However, the driver-passenger relationship is often overlooked in public transport. The drivers constantly need to cope with compelling and conflicting job demands. For example, in this study, some transport providers do not allow their drivers to carry passengers with disability during peak hours, yet some drivers acknowledge that passengers with disability should be treated the same way as other passengers. Both drivers of buses and mini-bus taxis stated that it was time-consuming to help passengers who use wheelchairs. At the same time it was unexpected that drivers expressed compassion for passengers with disability, as previous research reveals many drivers' negative attitudes. Although some drivers appeared to have empathy and humility towards passengers with disability, their actions do not match and often seem insensitive, for example, leaving behind passengers who use wheelchairs at bus stops. Therefore, drivers' encounters with passengers with disability should be understood and incorporated in transport planning to provide transport services that meet the needs of passengers with disability.

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Content and Effectiveness of Community-Based Rehabilitation on Quality of Life in People Post Stroke: a Systematic Review with Meta-Analysis

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ABSTRACT

Purpose: *The study aimed to review the content and evaluate the effects of CBR on quality of life (QoL), balance, and walking capacity for people post stroke, compared to other rehabilitation protocols or no care.*

Methods: *A systematic search and meta-analysis of clinical trials of CBR interventions for stroke survivors was conducted. Five online electronic databases (MEDLINE/PubMed, Web of sciences, Scopus, Hinari, and Pedro) were searched for articles published in English and French languages, from inception up to December 2021. Sixteen studies were included that reported on QoL outcomes from CBR interventions involving 1755 adults post stroke.*

Results: *The different CBR interventions that were selected were grouped into three clusters: a) exercise programmes, b) task-oriented training, and c) educational and taking-charge programmes. CBR interventions were more effective than other rehabilitation protocols (SMD=0.16[0.02, 0.30], P=0.03, I²=40%) on QoL for people with chronic stroke. The effects of interventions on walking capacity and balance demonstrated non-significant difference (SMD=0.31[-0.02, 0.64], P=0.06, I²=88%, and SMD= 0.20[-0.12, 0.53], P=0.22, I²=68%, respectively).*

Conclusion: *Current data indicates that CBR can be used in many forms or in combinations to benefit people with chronic stroke. Also, CBR is as effective as other rehabilitative protocols or no care on walking capacity and balance, while being more while being more effective than institution-based rehabilitation or no care effective than institution-based rehabilitation or no care, in improving quality of life which is a well-recognised goal in the rehabilitation of people with chronic stroke.*

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Key words: balance, community-based rehabilitation, quality of life, stroke, walking capacity

INTRODUCTION

Stroke is one of the three most common causes of death, along with malignant tumours and cardiovascular diseases, and is a leading cause of long-term disability in adults (Adoukonou et al., 2021; Feigin et al., 2014). The development of neurovascular units in recent years and thrombolytic treatments have reduced the mortality and sequelae associated with stroke (Navarrrro et al., 2021). However, the number of persons with disabilities who experience stroke is gradually increasing (Adoukonou et al., 2020). Loss of balance while walking is common after stroke (Chang et al., 2021; Kossi et al., 2021), with about 70% of people living at home post stroke reporting a fall within a year of their stroke (Beyaert et al., 2015; Kossi et al., 2021). Limited walking capacity restricts the person's independent mobility and can contribute to a sedentary lifestyle, increased disability and risk of recurrence, resulting in a poorer quality of life (Nindorera et al., 2021; Schmid et al., 2013). Previous studies have shown that motor function, balance, walking capacity and independence in activities of daily living are of importance for perceived health-related QoL (Langhammer et al., 2008, 2014; Nindorera et al., 2021). Better quality of life has been reported to be associated with greater independence in daily living and mobility (Heikinheimo & Chimbayo, 2015). Park and Kim (2019) found that gait function is essential for a better QoL in people post stroke. Therefore, to facilitate recovery after stroke, the implementation of rehabilitation is promoted, and a key rehabilitation goal for people post stroke is to improve walking capacity in order to enhance QoL (Corbetta et al., 2015).

Overall, despite being considered important indicators of post-stroke rehabilitation and recovery, global outcomes that represent the individual's functioning in society such as participation and perception of health-related QoL (HRQoL) have been less well reported (Desrosiers et al., 2008; Tyson & Turner, 2000). In most low- and middle-income countries, the weakness of a social security system, the delay in management of stroke cases and the inaccessibility of rehabilitation care reduce the chance of optimal functional recovery of people post stroke (Kossi et al., 2016). In low- and middle-income countries, resources for stroke care and rehabilitation are lacking and, following an acute stroke, many people are often discharged from hospital without an option of receiving adequate rehabilitation

by trained healthcare professionals (Wasserman et al., 2009). In addition to the cost of rehabilitation (Calvo et al., 2019; Ntsiea, 2019), the increased pressure to shorten the length of hospital stay and lack of access to affordable rehabilitative interventions have been reported to result in decreased QoL in people post stroke (Choi-Kwon et al., 2006; Mahesh et al., 2018). These challenges also make the burden of having stroke heavier in low- and middle-income countries than in high-income countries (Abegunde et al., 2007; Navarro et al., 2021). The prohibitive cost and limited access to conventional stroke rehabilitation has resulted in the development of other approaches, such as bringing the rehabilitation strategies into the home or community of people living with stroke, known as community-based rehabilitation (Iemmi et al., 2015; Ryan et al., 2006).

Since the '80s, community-based rehabilitation (CBR) has been presented as an approach for rehabilitation, resulting in feelings of empowerment and promotion of inclusion and participation of persons with disability (De Groote, 2019). It is a holistic strategy for rehabilitating persons with disabilities within the community, as compared to conventional rehabilitation programmes that are solely institutional or medical. It has been developed over the years, and recently the term CBR has been changed to "Community Based Inclusive Development" (CBID). The latter is a key approach to address the Convention on the Rights of Persons with Disabilities and leave no one behind in achieving the Sustainable Development Goals. CBID particularly promotes the participation and voice of people with disabilities in decision-making processes at the local level (De Groote, 2019). CBR is a term used widely in high-income countries as well, commonly described as rehabilitation by trained rehabilitation professionals, delivered outside of a hospital setting - often in the person's home (Tosoc & Lazaro, 2022). This refers to 'community-delivered rehabilitation' which needs to be distinguished from 'informal or self-directed rehabilitation' (Wade, 2003). Overall, CBR is a strategy for rehabilitation, equalization of opportunities, poverty reduction and social inclusion of people with disabilities. Many studies describe various strategies and techniques being implemented, especially in stroke rehabilitation (Graven et al., 2011; Iemmi et al., 2015; Magwood et al., 2020).

The long-term institutionalisation following a stroke often results in isolation from the mainstream of community, social life and activities (Mitchell, 1999). Several systematic reviews have shown a positive effect of CBR on cognition and functional independence in people post stroke (Mitchell, 1999; Ntsiea, 2019; Wade, 2003). However, as far as the authors of the current study are aware, few have

addressed the effectiveness of CBR on QoL. Indeed, eleven years ago, Graven et al. (Graven et al., 2011) studied the effect of 'CBR' delivered by allied health professionals and/or nursing staff on depression, participation, and QoL in people post stroke. The authors found limited to moderate evidence supporting some rehabilitation interventions delivered by allied health professionals in affecting the outcomes of depression, participation and HRQoL post stroke. In fact, their approach refers to the model of community-delivered rehabilitation rather than self-delivered rehabilitation.

Objective

The present study aimed to evaluate the efficacy of CBR on quality of life in people post stroke, compared to other rehabilitation protocols such as institution-based rehabilitation or no care. Secondary objectives included: (i) reviewing the content of CBR, and (ii) evaluating the effects of CBR on balance and walking capacity in people post stroke. This could result in valuable contributions to evidence of the effectiveness of CBR for people post stroke.

METHOD

Study Design

This systematic review and meta-analysis were performed according to the protocol registered in the international prospective register of systematic reviews, PROSPERO (<https://www.crd.york.ac.uk/PROSPERO>; no. CRD42020197264). The study complied with the preferred reporting items for systematic reviews and meta-analyses statement (Moher et al., 2009). Methodological issues were resolved with guidance from the Cochrane Handbook for systematic reviews of interventions (Higgins, s. d.).

Data Sources and Searches

Five electronic databases (MEDLINE/PubMed, Web of sciences, Scopus, Hinari, and Pedro) were searched for articles published in English and French languages, from inception to December 2021. The search strategy was adapted to each database, combining keywords and MeSH terms where applicable, using a combination of 'stroke', 'rehabilitation', 'care', 'management', and 'community'. The search was limited to randomised controlled trials and clinical trials. Additionally, published reviews and the reference lists of retrieved publications were searched manually. The full search strategy used for each database is presented in Supplementary material 1.

Supplementary material 1. Full search strategy in the five electronic databases

Databases	Search equations	Filters	Results	Dates
Pubmed	((stroke) OR (Cerebrovascular accident)) AND ((Community-based rehabilitation) OR (Community-based inclusive development)) AND (Quality of life)	Full text, Clinical Trial, Randomized Controlled trial, Humans, English, French	42	29/09/2021
Web of science	((stroke) OR (Cerebrovascular accident)) AND ((Community-based rehabilitation) OR (Community-based inclusive development)) AND (Quality of life)	Rehabilitation or Clinical, Neurology or Health Care Sciences Services or Neurosciences or Primary Health Care or Social Work or Social Sciences Biomedical or Social Sciences, Articles	75	29/09/2021
Scopus	((stroke) OR (Cerebrovascular accident)) AND ((Community-based rehabilitation) OR (Community-based inclusive development)) AND (Quality of life)	LIMIT-TO (OA , "all") AND (LIMIT TO (DOCTYPE , "ar")) AND (LIMIT-TO (SUBJAREA , "MEDI") OR LIMIT-TO (SUBJAREA , "HEAL") OR LIMIT-TO (SUBJAREA , "NURS") OR LIMIT-TO (SUBJAREA , "SOCI")) AND (LIMIT-TO (LANGUAGE , "English"))	36	29/09/2021
Hinari	((Abstract:(stroke)) OR (Cerebrovascular accident)) AND ((Community-based rehabilitation) OR (Community-based inclusive development)) AND (Abstract:(Quality of life))	Full text online; journal articles; Discipline: (occupational therapy & rehabilitation, physical therapy, social welfare & social work); Subject Terms: rehabilitation, humans, stroke, adult, health care sciences & services, health-related quality of life, physical fitness, physical activity, physical medicine and rehabilitation, physical therapy, physiotherapy, quality of life. Language (English, French)	113	29/09/2021
Pedro	Stroke, community-based rehabilitation, quality of life	-	30	29/09/2021

Inclusion criteria:

Studies were included if they were randomised controlled trials or non-controlled clinical trials and reported on outcomes of interventions addressing the effect of community-based rehabilitation on QoL as primary or secondary outcome. To be included, studies had to report on adults (age ≥ 18 years) with a confirmed diagnosis of a stroke.

Exclusion criteria:

Studies involving post-stroke people aged < 18 years, as well as those involving other diagnosis than stroke, were excluded. Studies were excluded if they did not investigate QoL as primary or secondary outcomes and in which the setting was not community-based.

Interventions and Comparators

For this review, interventions were defined as rehabilitation provided by the community, family and/or self-training at home or supervised by a professional (Ru et al., 2017). This refers to 'informal or self-directed rehabilitation'.

Inclusion criteria:

Any CBR programmes as compared with any other rehabilitative strategies intended to improve the QoL of people with stroke or no care, were included.

Exclusion:

Interventions delivered in hospital, including day units and outpatient departments as well as those delivered by healthcare professionals and allied healthcare professionals within an institution, were excluded from this review.

Study Tools

QoL outcome should have been evaluated in people post-stroke using valid tools such as: Stroke Impact Scale (SIS) (Mulder & Nijland, 2016), Stroke Specific Quality of Life Scale (SS-QOL) (Post et al., 2011; Williams et al., 1999), Stroke and Aphasia Quality of Life scale (SAQoL) (Hilari et al., 2003), Short Form 36 (SF-36) (Brazier et al., 1992), EuroQol (Golicki et al., 2015), WHOQoL-Bref (Skevington, 1999), etc. The secondary outcomes should have included balance (measured using Berg Balance Scale –BBS (Blum & Korner-Bitensky, 2008); Timed Up and Go Test -TUG (Podsiadlo & Richardson, 1991) etc.) and walking capacity (evaluated by 6MWT (Cheng et al., 2020; Kervio et al., 2004); 10MWT (Cheng et al., 2020), etc.).

Data Collection and Analysis

Extraction of data and quality assessment

The first and second authors independently screened the titles and abstracts of all unique records for relevance. Full texts of selected papers were reviewed, and data was extracted using an Excel spreadsheet. Differences were discussed until consensus was reached between the two reviewers. If necessary, a third author was consulted. For RCTs, data was extracted at baseline, after the intervention, and when available at follow-up time points. The descriptive outcomes included sociodemographic (sex, age, geographical area, etc.) and clinical characteristics (type of stroke, paretic side, stroke duration, etc.).

The first two review authors assessed the methodological quality of included RCTs using the Physiotherapy Evidence Database (PEDro) scale which is an 11- item scale designed for rating of the methodological quality of randomised trials (Blobaum, 2006). Each item can contribute 1 point to the total PEDro score (1=satisfied, 0=not satisfied; maximum=10 points); exception is item 1 which is related to the external validity or generalisability of the sample (Moseley et al., 2002; Teasell et al., 2003). For clinical trials, the Newcastle Ottawa Scale (NOS) was used, which assesses the quality of non-randomised and non-controlled studies. The NOS evaluates 3 quality parameters (selection, comparability, and outcome) divided across 8 specific items, which slightly differ when scoring case control and longitudinal studies (Wells et al., 2012). Each item on the scale is scored for 1 point, except for comparability which can be adapted to the specific topic of interest to score up to 2 points. Thus, the maximum score for each study is 9, with studies having less than 5 points being identified as representing at high risk of bias (Luchini et al., 2017). In case of disagreement between the review authors, a third author (TA) was consulted.

Data Synthesis and Analysis

To describe the content of CBR, exploratory subgroup analyses were conducted based on intervention type. For the meta-analysis, standardised mean differences (SMD) with 95% confidence intervals (CI) were calculated. The SMD reflects the intervention effect size (ES) in each study relative to the variability observed in that study. An SMD of '0' means that the treatment and control have equivalent effects. Improvement is associated with higher scores on the outcome measure. SMDs >0 or <0 indicate the degree to which the treatment is more or less effective,

respectively, than the control. Effect size (ES) was calculated based on means and standard deviations, and on the size of the intervention and control groups. ES calculated with SMD was interpreted using Cohen's method (Cohen, 1988) and classified as small (0.20), medium (0.50), and large (0.80). The results of the Chi-squared test (significance level: 0.05) were checked to assess the heterogeneity of included studies and the I^2 statistic to quantify consistency. An I^2 value of 50% or higher indicated the presence of substantial heterogeneity. Statistical analyses were performed using a random-effects model with Review Manager Software (Version 5.3).

Ethical Considerations

This systematic review and meta-analysis did not require ethical approval because data was analysed anonymously.

RESULTS

Identification and Selection of Studies

The process by which articles were selected is illustrated in Figure 1. The authors identified 296 records in the electronic database. After duplicate removal, 263 records were screened by title and abstracts, after which 21 articles were deemed to be potentially relevant and 8 studies were excluded after full text scrutiny. The reasons for exclusion included: QoL not reported in the outcomes (n=2), setting was not community-based (n=1), participants without stroke (n=1), no intervention reported (n=4). Ultimately, 16 studies were eligible for analysis and synthesis and met the study's inclusion criteria.

Figure 1: Flowchart of Study Selection and Inclusion

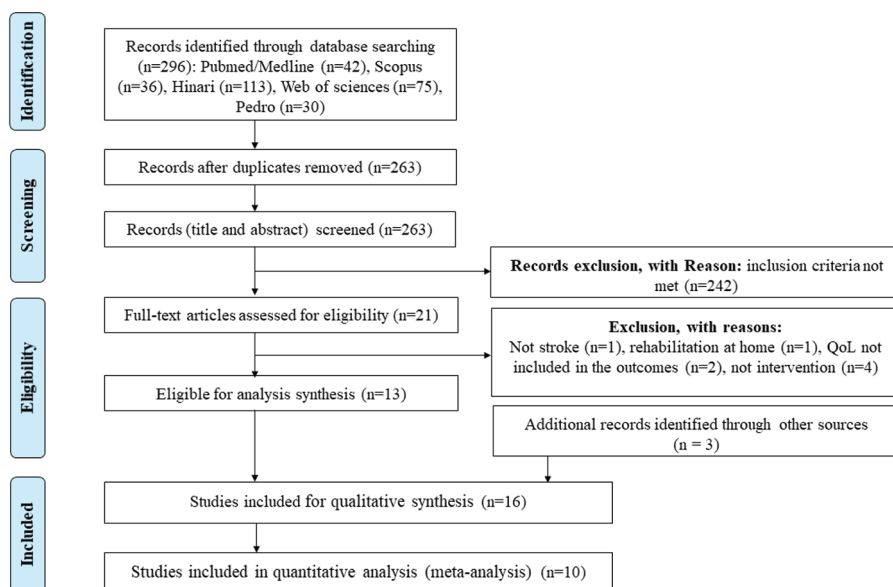


Table 1. Patient characteristics in the included studies

Study ID	Country	Experimental group							Control group						
		Size (n)	Mean age (mo) ± SD	Time since stroke (mo)	Sex (%)			Side of injury (%)	Size (n)	Mean age (mo) ± SD	Time since stroke (mo)	Sex (%)			Side of injury (%)
					M	Is	He					RH	M	Is	
Calugi et al (2016)	Italy	126	71.8±10.5	9.58±4.23	67.5	NR	NR	63.3	103	70.1±10.7	6.47±4.27	60.2	NR	NR	47.5
Dean et al. (2018)	England	23	70±12	16.67	70	65	13	NR	22	71±10	16.2	67	68	1	NR
Dunn et al. (2017)	Australia	20	60.1±19	5.3±3.5	40	NR	NR	NR	NA	NA	NA	NA	NA	NA	NA
Ellis-Hill et al. (2019)	England	29	72.0±11.2	7(1–32)	41	75	20	38	27	67.4±12.8	7(2–19)	74	74	22	50
Fu et al. (2020)	New Zealand	E1 132	71.4±12	1.5±0.81	56.1	NR	NR	NR							
		E2 138	71.7±12	1.5	61.6	NR	NR	NR	130	73±12.2	1.5	57.7	NR	NR	NR
Gordon et al (2013)	India	64	63.4±9.4	12.8±3.6	45.3	87.3	12.7	56.3	64	64.9±11.1	11.8±3.6	45.3	84.3	7.2	65.6
Harrington et al. (2010)	England	119	71±10.5	10.3	55	NR	NR	41	124	70±10.2	10.3	54	NR	NR	45
Hartman-Maeir et al. (2007)	Israel	27	61.6±7	35.20	56	NR	NR	56	56	57.7±11	11.6±7.2	75	NR	NR	57
Jagroop et al. (2018)	Canada	10	72.7±9	NR	90	10	20	40	NA	NA	NA	NA	NA	NA	NA
Lai et al. (2004)	China	21	69.5±6	36±24	57	76	24	NR	NA	NA	NA	NA	NA	NA	NA
Malagoni et al. (2016)	Italy	6	62.5±13.8	6.2±3.5	67	67	33	33	6	70.7±9.0	6.8±4.1	83	67	33	50

Author (Year)	Country	E1	93		61	NR	NR	NR	NA	NA	NA	NA	NA	NA	NA	
			E2	61±12												30±26.4
Mayo et al. (2015)	Canada	93	65±11	37.2±37.2	60	NR	NR	NR	NA	NA	NA	NA	NA	NA	NA	NA
Mohd Nordin et al. (2019)	Malaysia	42	60	16	81	61.9	28.6	50	46	59.5	NR	78.3	47.8	32.6	43.5	
Stuart et al. (2009)	Italy	40	66.8±1	50.4±9.6	62.5	NR	NR	35	38	70±1.7	42±6	76.3	NR	NR	50	
Sullivan et al. (2014)	United States	11	60.4±12	146.4±92.4	54.6	NR	NR	36.4	NA	NA	NA	NA	NA	NA	NA	
Taylor-Piliae (2014)	United States	97	70.5±9.81	36±49.5	54.8	67.5	20.4	30.2	48	68.2±10.3	38.7±46.7	47.9	62.5	29.2	29.2	

M = Male; Is = Ischemic; He = Hemorrhagic; RH = Right Hemisphere; E1 = Experimental 1; E2 = Experimental 2; NA = non-applicable ; NR = non reported

Studies and Participants' Characteristics

The 16 included studies involved a total of 1755 participants, with sample sizes ranging from 6 to 400. The reported mean/median ages of participants ranged from 60 years to 72.7 years for those receiving the intervention, and from 55.8 years to 73 years for controls. The proportion of male participants ranged from 40% to 90%, while time since stroke ranged from 1.5 to 146 months. The studies included in this review spanned a period of 17 years from 2004 – 2020. Articles were all published in peer-reviewed journals. All of the studies were implemented in the community or home-based setting. Eight randomised controlled trials and eight clinical trials were found. A summary of the included studies is compiled in Table 1 and additional details of included studies' characteristics are given in Table 2.

Table 2: Additional details on the studies characteristics

Study ID	Design	Interventions		Outcomes measures	Results reported
		Experimental group	Control group		
Calugi et al (2016)	CT	Content: APA-TPE (adaptive physical activity combined with therapeutic patient education) - APA including mobility, balance and stretching exercises - TPE including an overview of stroke risk factors, the potential for recovery, how to cope with disabilities and the benefits of a healthy lifestyle Modality: individual & group training Setting: community	TAU = treatment as usual (usual care)	Ability to perform ADLs (Modified BI); Caregiver burden (CSI); Depression (GDS) and Health-related quality of life (SF-12).	The physical component of SF-12 showed a faster increase in the experimental group compared with the TAU group (t=-1,91; p=0,058) but the difference between groups did not reach statistical significance
Dean et al. (2018)	RCT	Content: ReTrain (Rehabilitation Training) followed by three drop-in sessions over the subsequent 3 months Modality: individual & group training Setting: home & community	Usual care & advice booklet about exercise after stroke	QoL (SQoL, SF 12, EQ-5D-5L) Functional mobility (RMI, TUG, modified PSFS) and physical activity (accelerometer); SSEQ, FAS, EBESSE.	ReTrain is feasible, acceptable and safe.

Dunn et al. (2017)	CT	Content: The HowFITSS intervention including a manual provided to each participant Modality: individual training Setting: home & community	Waiting list	QoL (SAQoL); Walking speed (10MWT), Balance (Step test), fatigue (FAS), depression (PHQ).	Small significant improvements on the SAQoL ($p < 0.001$).
Ellis-Hill et al. (2019)	RCT	Content: Artist-facilitated arts and health group intervention (HoS) plus usual care (UC) Modality: group training Setting: Community	usual care (UC)	HRQoL (SF-36); well-being (WEMWBS); mood (HADS); capability (ICECAP-A); self-esteem and self-concept (RSES, HISDS-III);	Preliminary effect sizes for candidate primary outcomes were in the direction of benefit for the HoS arm.
Fu et al. (2020)	RCT	Content: Take Charge (community-based self-directed rehabilitation intervention) Modality: individually training Setting: home	Written educational material about stroke	QoL as assessed SF-36 PCS; ADLs and independence by SF-12 PCS, BI, FAI, EQ VAS, CSI;	Take Charge improves QoL ($p = 0.004$), which is sustained at 12 months ($p < 0.001$)
Gordon et al. (2013)	RCT	Content: walk briskly along a prescribed course for 15 minutes, 3 times per week, for 12 weeks, initially, progressing by 5 minutes per week up to 30 minutes in their home or community. Modality: group training Setting: Community	light massage to the affected limbs for 25 minutes, 3 times per week, for 12 weeks, at home	Health-related quality of life (SF-36); Functional status (BI and Older Americans Resource and Services scale); Endurance (6MWT); Lower extremity strength.(Motricity Index).	There was a trend toward greater improvement over time for the Physical Health Component of the SF-36 ($P = 0.077$) and significantly greater improvement over time for distance walked in 6 minutes in favor of the walking group ($P < 0.001$).
Harrington et al. (2010)	RCT	Content: Exercise and education schemes facilitated by volunteers and qualified exercise instructors (supported by a physiotherapist) Modality: individual & group training Setting: home & community	Standard care & information sheet	QoL (WHOQoL-Bref); ADLs (FAI); Functional mobility (RMI); balance (TUG); depression (HAD); strain related to care provision (CSI); social care and personal costs (NHS and PSS); social and physical integration in stroke survivors (SIPSO)	A significant improvement was demonstrated on the psychological component of WHOQoL-bref at six months ($p = 0.011$).
Hartman-Maeir et al. (2007)	CT	Content: Community-based rehabilitation program Modality: group training Setting: community	No care	Health status or QoL (SIS); ADLs, functional assessment and levels of disability (FIM, IADLq); Leisure participation (ACS) and satisfaction from life areas (LiSat-9);	Not advantage in terms of disability levels ($p = 0.004$). The activity level increased due to the program ($P < 0.001$) and the satisfaction scores were higher than non-participants ($p < 0.05$).
Jagroop et al. (2018)	CT	Content: Community-based exercise program: a warm-up, aerobic, resistance, balance, and flexibility exercises. Modality: group training Setting: community	No control group	QoL (SSQoL); ADLs (Sit to stand, 6MWT, TUG, BBS); Program effectiveness (ESES).	A trend for significant improvements for QoL ($p = 0.085$) and for ADLs ($p = 0.01$).
Lai et al. (2004)	CT	Content: Educational talks, exercise (strength and balance) and psychosocial support, conducted by a physiotherapist via a videoconference link Modality: individual training Setting: community	No control group	QoL (SF-36); Balance (BBS); Self-esteem (SSES); Depression (GDS-15); Locomotion, balance and key position changes (EMS); ADL (Lawton IADL).	Feasibility, efficacy ($p < 0.001$) and high level of acceptance of telerehabilitation for community-dwelling stroke clients.

Malagoni et al. (2016)	RCT	Content: Ti-To rehabilitation program consisted of a structured home based phase performed alternately. Modality: individual training Setting: home-based	Supervised standard rehabilitation program	QoL (SF-36); 6MWT, TUG Feasibility and satisfaction (CSQ-8)	Improvements in functional capacity and quality of life (p=0.03)
Mayo et al. (2015)	CT	Content: Evidence-based program delivered in three 12-week sessions including exercise (aerobic exercise, strength of peripheral and core musculature, balance, flexibility, and rapidity of movements) and project-based activities, done as individuals and in groups Modality: individual & group training Setting: community	No control group	Hours spent per week in meaningful activities outside of the home; Reintegration to Normal Living Index; Stroke-Specific Geriatric Depression Scale; gait speed; EQ-5D and Preference-Based Stroke Index.	Over 45% of people met or exceeded the pre-specified target of a three hour per week increase in meaningful activity and this most often took a full year of intervention to achieve. Greatest gains were in satisfaction with community integration (mean 4.78; 95% CI: 2.01 to 7.55) and stroke-specific health related quality of life (mean 4.14; 95% CI: 2.31 to 5.97).
Mohd Nordin et al. (2019)	RCT	Content: Career-assisted therapy conducted at home: task-oriented activities consisting of a set of physical activities and a set of domestic tasks, cognitive or brain stimulating activities and leisure activities. Modality: group training Setting: home	Usual therapy implemented in out-patient hospital setting	Health-related QoL (EQ-5D-5L and EQ VAS); Mobility level (RMI); Balance (BBS); lower limb strength (FTSS); Gait speed (10MWT);	Both therapy groups improved significantly in all the functional measures; mobility (p < 0.01), balance (p < 0.01), lower limb strength (p < 0.01), gait speed (p < 0.05), and in the quality of life score (p < 0.05)
Stuart et al. (2009)	nRCT	Content: Community-based progressive group exercise regime that included walking, strength, and balance training for 1 hour, thrice a week, in local gyms, supervised by gym instructors Modality: group training Setting: community	Usual care	QoL (SIS); Gait velocity (6MWT); Depression (HRS); Stroke impairments (Motricity Index); Mobility (SPPB, 6MWT, BBS); Basic ADL (BI)	APA-stroke appears to be safe, feasible, and efficacious in a community setting (P < 0.00015).
Sullivan et al. (2014)	CT	Content: Pedometer monitored, community-based intervention: to wear pedometers on the nonparetic hip during all waking hours, 7 days a week for 6 weeks. Modality: individual training Setting: community	No control group	QoL (SIS-16); Walking endurance and walking speed (6MWT and 10MWT); Balance self-efficacy (ABC); Captures satisfaction (Pedometer Satisfaction Survey).	There were moderate effect sizes for changes in SIS-16 (0.312) and 6MWT (0.293). Increasing steps correlated with increased perception of physical function.
Taylor-Piliae et al. (2014)	RCT	Content: Yang style 24-posture short-form TC (n=53), strength and range of movement exercises (SS) (n=44) while 1-hour class 3 times a week for 12 weeks. Modality: group training Setting: community	Written materials and resources for participating in community-based physical activity. In addition, they weekly phone call to inquire of their health status to provide individual attention.	Physical function (SPPB, fall rates, and 2-minute step test; Quality of life (SF-36, Center for Epidemiologic Studies Depression Scale, and Pittsburgh Sleep Quality Index)	All groups reported better perceived physical (SF-36 physical composite score: F1,142=4.15, P=0.04) and mental health (SF-36 mental composite score: F1,142=15.60, P<.01). Post hoc tests indicated that there was no significant change in perceived physical health for any of the groups (P>.05); however, all groups had significant improvements in perceived mental health after the 12-week intervention (P<.05)

SF-36 PCS: Physical Component Summary score of the Short Form 36 ; **BI:** Barthel Index; **FAI:** Frenchay Activities Index ; **MRS:** Modified Rankin Scale; **CSI:** Caregiver Strain Index ; **EQ-5D-5L:** Euroqol ; **SSQoL:** Stroke-Specific Quality of Life; **ADLs:** Activities of daily living; **BBS:** Berg Balance Scale ; **6MWT:** 6-minute walk test; **SQoL:** Stroke Quality of Life; **RMI:** Rivermead Mobility Index; **TUG:** Timed Up and Go Test; modified **PSFS:** modified Patient-Specific Functional Scale; **SSEQ:** Stroke Self-Efficacy Questionnaire; **FAS:** Fatigue Assessment Scale; **EBESE:** Exercise Beliefs and Exercise Self-Efficacy questionnaires; **SAQoL:** Stroke and Aphasia Quality of Life; **CRF :** Cardiorespiratory fitness; **HRQoL :** ambulation and health-related quality of life ; **SWT:** Shuttle Walk Test ; **cGXT:** cycle graded exercise test; **10MWT:** 10-meter walk test; **PHQ:** Patient Health Questionnaire ; **WHOQoL-Bref:** World Health Organization Quality of Life; **HAD:** Hospital Anxiety and Depression; **NHS:** National Health Service ; **PSS:** Personal Social Services; **SIPSO:** Subjective Index of Physical and Social Outcome; **FIM:** Functional Independence Measure; **IADLq:** Instrumental Activities of Daily Living Questionnaire ; **ACS:** Activity Card Sort; **Li-Sat:** Life-Satisfaction questionnaire ; **SIS:** Stroke Impact Scale; **GDS-15:** Geriatric Depression Scale 15-item Short Form; **EMS:** Elderly Mobility Scale ; **FTSS:** Five Times Sit to Stand; **EQ VAS:** EQ-Visual analogue Scale ; **CIRS:** Cumulative Illness Rating Scale ; **MMSE:** Mini-Mental State Examination; **HRS:** Hamilton Rating Scale ; **SPPB:** Short Physical Performance Battery. **WEMWBS:** Warwick-Edinburgh Mental Well-being Scale; **HADS:** Hospital Anxiety and Depression Scale; **ICECAP-A:** ICEpop CAPability measure for adults; **RSES :** Rosenberg Self-Esteem Scale; **HISDS-III:** Head Injury Semantic Differential Scale.

CBR, Community based rehabilitation; **RCT,** Randomized controlled trial; **TC,** Take Charge ; **CT,** Clinical trial ; **NA,** non-applicable

Methodological Quality Assessment

Eight RCTs of the included trials were of high quality (PEDro score ≥ 8 ; Supplementary material 2)(Calugi et al., 2016; Fu et al., 2020; Gordon et al., 2013; Harrington et al., 2010; Nordin et al., 2019; Taylor-Piliae et al., 2014). The assessment by the NOS also showed that the seven other included studies have an average methodological quality ($4 < \text{NOS score} \leq 8$)(Calugi et al., 2016; Dunn et al., 2017; Jagroop et al., 2018; Lai et al., 2004; Sullivan et al., 2014) and no studies were of low methodological quality (Supplementary material 3).

Supplementary material 2. Methodological quality assessment of included studies with PEDro scale

Study	A	B	C	D	E	F	G	H	I	J	Score/10	Level
Calugi et al. (2016)	N	N	Y	N	N	N	Y	Y	Y	Y	5	3
Dean et al. (2018)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	10	1
Ellis-Hill et al. (2019)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	10	1
Fu et al. (2020)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	10	1
Gordon et al. (2013)	Y	NC	Y	Y	Y	NC	Y	Y	Y	Y	8	1
Harrington et al. (2010)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	10	1
Malagoni et al. (2016)	Y	Y	Y	Y	Y	NC	Y	Y	Y	NC	8	1
Mohd Nordin et al. (2019)	Y	Y	Y	Y	Y	Y	Y	Y	Y	NC	9	1
Stuart et al. (2009)	N	N	Y	N	N	N	Y	Y	Y	Y	5	3
Taylor-Piliae et al. (2014)	Y	Y	Y	Y	Y	Y	Y	Y	Y	NC	9	1

Y = yes; N = no; NC = not clear.

A = random allocation; B = concealed allocation; C = groups similar at baseline; D = participant blinding; E = therapist blinding; F = assessor blinding; G = <15% dropout; H = intention-to-treat analysis; I = between group difference reported; J = point estimate and variability reported.

Levels: 1 = score 8–10 (excellent quality); 2 = score 6–7 (good quality); 3 = score 4–5 (fair); 4 = score < 4 (poor quality)

Supplementary material 3. Methodological quality assessment of included studies with New Castle Ottawa scale

Authors(years)	Study design	A	B	C	D	E	F	G	H	I	Score/9	Level
Calugi et al. (2016)	Non randomized controlled trial	0	1	0	0	0	1	1	1	1	5	Average
Dean et al. (2018)	Randomized controlled trial	1	1	1	1	1	1	1	1	1	9	High
Dunn et al. (2017)	Clinical trial	1	0	1	1	0	0	1	1	1	6	Average
Ellis-Hill et al. (2019)	Randomized controlled trial	1	1	1	1	1	1	1	1	1	9	High
Fu et al. (2020)	Randomized controlled trial	1	1	1	1	1	1	1	1	1	9	High
Gordon et al. (2013)	Randomized controlled trial	1	1	1	1	0	1	1	1	1	8	High
Hartman-Maeir et al. (2007)	Non randomized controlled trial	1	0	1	1	1	1	1	1	1	8	High
Harrington et al. (2010)	Randomized controlled trial	1	1	1	1	1	1	1	1	1	9	High
Jagroop et al. (2018)	Clinical trial	1	0	1	1	0	0	1	0	1	5	Average
Lai et al. (2004)	Clinical trial	1	0	1	1	0	0	1	0	1	5	Average
Malagoni et al. (2016)	Randomized controlled trial	1	1	1	1	1	1	1	0	0	7	High
Mayo et al. (2015)	Clinical trial	1	1	0	0	0	1	1	1	0	5	Average
Mohd Nordin et al. (2019)	Randomized controlled trial	1	1	1	1	1	1	1	0	0	7	High
Stuart et al. (2009)	Non randomized controlled trial	1	1	1	0	1	0	1	0	0	5	Average
Sullivan et al. (2014)	Clinical trial	1	0	1	1	0	0	1	0	0	4	Average
Taylor-Piliae et al. (2014)	Randomized controlled trial	1	1	1	1	1	1	1	1	0	9	High

Risk of Bias Assessment

The overview of the risk of bias ratings was as follows (Supplementary material 4): 10 studies out of 16 reported appropriate generation of a random allocation sequence (Dean et al., 2018; Dunn et al., 2017; Fu et al., 2020; Gordon et al., 2013; Harrington et al., 2010; Mayo et al., 2015; Nordin et al., 2019; Taylor-Piliae et al., 2014); 8 studies out of 16 presented concealment of the allocation sequence (Dean et al., 2018; Dunn et al., 2017; Gordon et al., 2013; Harrington et al., 2010; Nordin et al., 2019; Taylor-Piliae et al., 2014); 6 studies described blinding of participants and personnel (Dean et al., 2018; Ellis-Hill et al., 2015; Gordon et al., 2013; Malagoni et al., 2016; Nordin et al., 2019; Taylor-Piliae et al., 2014); all studies described blinding of the outcome assessment and exhibited non-selective reporting; and 5 studies had uncertain complete outcome data (Calugi et al., 2016; Hartman-Maeir et al., 2007; Jagroop et al., 2018; Malagoni et al., 2016; Stuart et al., 2009).

Supplementary material 4. Evaluation of the risk of bias in the included studies by the Cochrane risk of bias assessment tool

Studies	Random sequence generation	Allocation concealment	Blinding of participants and personnel	Blinding of outcome assessment	Incomplete outcome data	Selective reporting	Other bias	Total /7
Calugi et al. (2016)	-	-	-	+	?	+	?	2
Dean et al. (2018)	+	+	+	+	+	+	+	7
Dunn et al. (2017)	+	+	-	+	+	+	+	6
Ellis-Hill et al. (2019)	+	+	+	+	+	+	+	7
Fu et al. (2020)	+	+	?	+	+	+	+	6
Gordon et al. (2013)	+	+	+	+	+	+	+	7
Harrington et al. (2010)	+	+	-	+	+	+	+	6
Hartman-Maeir et al. (2007)	-	-	-	+	?	+	+	3
Jagroop et al. (2018)	-	-	-	+	?	+	+	3
Lai et al. (2004)	-	-	-	+	+	+	+	4
Malagoni et al. (2016)	+	-	+	+	?	+	+	6
Mayo et al. (2015)	+	-	-	+	+	+	+	5
Mohd Nordin et al. (2019)	+	+	+	+	+	+	+	7
Stuart et al. (2009)	?	-	-	+	?	+	?	2
Sullivan et al. (2014)	-	-	-	+	+	+	+	4
Taylor-Piliae et al. (2014)	+	+	+	+	+	+	+	7

+, Low risk; -, High risk; ?, Unclear

Content of CBR Interventions

The CBR interventions were clustered into three groups: a) exercise programme, b) task-oriented training, and c) educational and taking-charge programmes, as shown in Figure 2.

Figure 2: CBR Interventions clustered into three groups

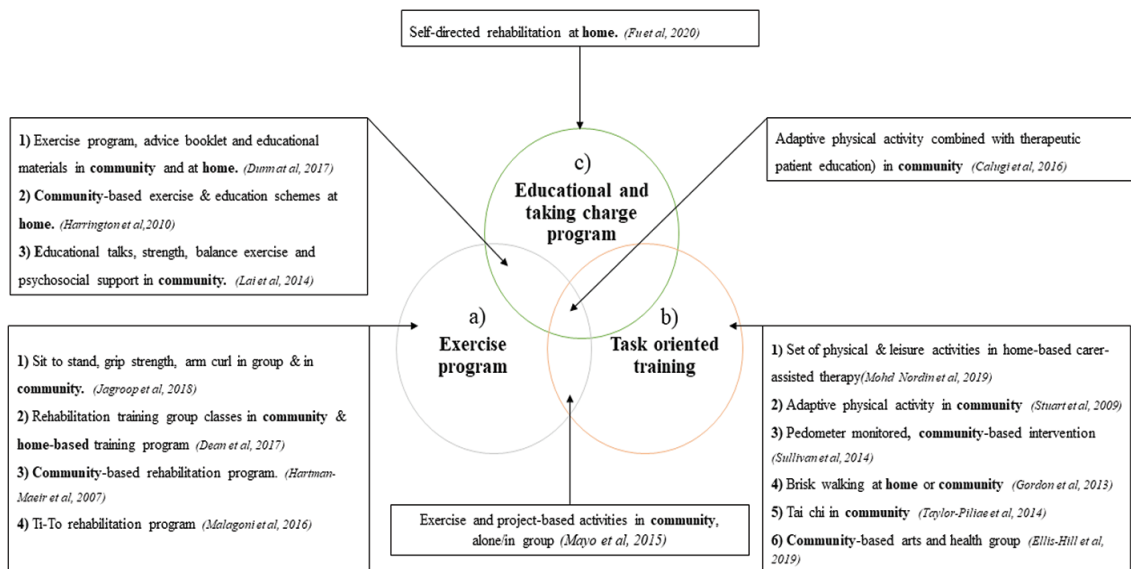


Figure legend: a) Exercise programme, b) Task-oriented training, and c) Educational and taking-charge programme

- a) Exercise programme** - Within this group, 9 studies (Calugi et al., 2016; Dean et al., 2018; Dunn et al., 2017; Harrington et al., 2010; Hartman-Maeir et al., 2007; Jagroop et al., 2018; Lai et al., 2004; Malagoni et al., 2016; Mayo et al., 2015) used this type of intervention in the form of an exercise programme (aerobic, resistance, balance, flexibility exercises, strength of peripheral and core musculature); rehabilitation training, progressive group exercise including walking, strength, and balance. All interventions were 'community-delivered rehabilitation' supervised by a professional (such as a physiotherapist, qualified exercise instructors, training volunteers).
- b) Task-oriented training** - Eight studies (Calugi et al., 2016; Ellis-Hill et al., 2015; Gordon et al., 2013; Mayo et al., 2015; Nordin et al., 2019; Stuart et al., 2009; Sullivan et al., 2014; Taylor-Piliae et al., 2014) utilised this type of CBR, namely a set of physical activities, set of domestic tasks, cognitive or brain stimulating activities and leisure activities, project-based activities, pedometer monitored, community-based intervention, adaptive physical activity, tai chi, etc.
- c) Educational and taking-charge programme** - This intervention concerns 5 studies (Calugi et al., 2016; Dunn et al., 2017; Fu et al., 2020; Harrington et al.,

2010; Lai et al., 2004) and aimed to provide participants with an overview of stroke risk factors, the potential for recovery, how to cope with disabilities and the benefits of a healthy lifestyle, educational schemes and talks. All this reinforces the verbal information and self-directed rehabilitation intervention. Regardless of the type or form of the different procedures, they were performed individually at home and/or in groups, but the most important was the combination of the different intervention types of CBR. One study (Mayo et al., 2015) combined the (a) and (b) intervention types; 3 studies (Dunn et al., 2017; Harrington et al., 2010; Lai et al., 2004) combined intervention types (a) and (c); and 1 study (Calugi et al., 2016) combined all three CBR intervention formats. Also, the majority of the interventions were hybrid (a community-delivered rehabilitation and self-delivered rehabilitation).

Type of Experimental and Control Interventions

Figure 3 depicts the interventions executed in the ten trials included in this meta-analysis. CBR interventions were compared to usual care with physical training component (Calugi et al., 2016; Nordin et al., 2019; Stuart et al., 2009), or usual care without a physical training component (massage, information sheet, advice booklet, or no care) (Gordon et al, 2013; Fu et al, 2020), or a combination of both control interventions (Harrington et al, 2010; Taylor-Piliae et al, 2014; Dean et al, 2018).

Volume of the Interventions

Interventions were conducted at a frequency of 1 to 5 times per week, with duration of generally ≥ 30 minutes per session. The duration of the experimental intervention varied from 6 to 48 weeks, while little data was reported for the control group. The details for the volume of interventions administered to the participants are presented in Table 3.

Figure 3: Classification of interventions executed in the ten trials included in this meta-analysis

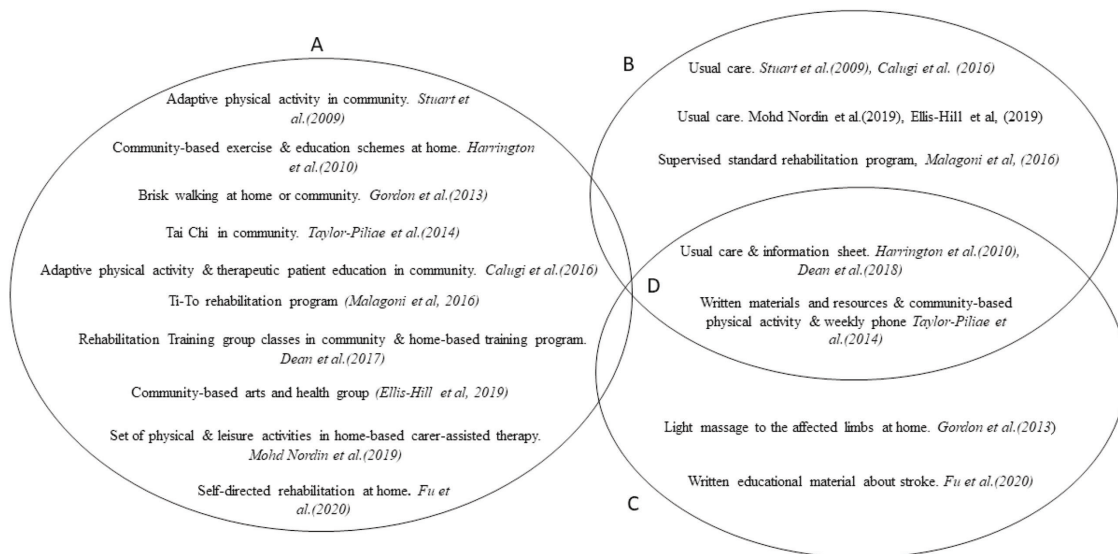


Figure legend : A, Experimental intervention; B, Control intervention with physical training component; C, Control intervention without physical training component; D, combination of both control interventions

Table 3. Summary of the volume of the experimental and control interventions

Studies	Experimental				Control			
	Duration (weeks)	Frequency (times/week)	Volume/session (min)	Total training time (min)	Duration (weeks)	Frequency (times/week)	Volume/session (min)	Total training time(min)
Calugi et al. (2016)	8	2	NR	NR	NR	NR	NR	NR
Dean et al. (2018)	12	2	120	1440	12	NR	120	1440
Dunn et al. (2017)	12	NR	30	360	NA	NA	NA	NA
Ellis-Hill et al. (2019)	14	NR	120	1200	NR	NR	NR	NR
Fu et al. (2020)	48	NR	NR	NR	NR	NR	NR	NR
Gordon et al. (2013)	12	3	30	NA	12	3	25	NA
Hartman-Maeir et al. (2007)	NR	NR	NR	NR	NR	NR	60	NR
Harrington et al. (2010)	8	2	120	960	8	NR	NR	NR
Jagroop et al. (2018)	9	1	60	540	NA	NA	NA	NA
Lai et al. (2004)	8	1	90	720	NA	NA	NA	NA

Malagoni et al. (2016)	10	6	2 X 10	1200	10	3	60	1800
Mayo et al. (2015)	12	2	180	4320	NA	NA	NA	NA
Mohd Nordin et al. (2019)	12	3	180	2160	12	NR	120	1440
Stuart et al. (2009)	24	3	180	4320	24	NR	NR	NR
Sullivan et al. (2014)	6	5	NR	NR	NA	NA	NA	NA
Taylor-Piliae et al. (2014)	12	3	60	2160	12	NR	NR	NR

NA, not applicable; NR, not reported

Outcome Descriptions

All included studies reported on the primary outcome measure (Supplementary material 5). A variety of standardised assessment tools and self-reported measures were used to evaluate the effectiveness of CBR on:

- **Quality of life:** reported by the 16 studies using the short form SF-36 (n=7), the Stroke-Specific Quality of Life (SSQoL) (n=2), Stroke Impact Scale (SIS) (n=3), World Health Organisation Quality of Life-BREF (WHOQoL-Bref) (n=1), Euroqol (EQ-5D-5L) (n=2) and Stroke and Aphasia Quality of Life (SAQoL) (n=1).
- **Walking capacity** (n=8): 6-minute walk test (6MWT) (n=6) and 10-metre walk test (10MWT) (n=3).
- **Balance** (n=8): Berg Balance Scale (BBS) (n=4) and Timed Up and Go Test (TUG) (n=4).

Supplementary material 5. Outcome measures used in the included studies

OUTCOME MEASURE	STUDY ID															
	Calugi et al. (2016)	Dean et al. (2018)	Dunn et al. (2017)	Ellis-Hill et al. (2019)	Fu et al. (2020)	Gordon et al. (2013)	Hartman-Maeir et al. (2007)	Harrington et al. (2010)	Jagroop et al. (2018)	Lai et al. (2004)	Malagoni et al. (2016)	Mayo et al. (2015)	Mohd Nordin et al. (2019)	Stuart et al. (2009)	Sullivan et al. (2014)	Taylor-Piliae et al. (2014)
Quality of life																
short form (SF-36)	X			X	X	X				X	X					X
Stroke-Specific Quality of Life (SSQoL)		X							X							
Stroke Impact Scale (SIS)							X							X	X	

World Health Organization Quality of Life Stroke Quality of Life (WHOQoL-Bref)								X									
Euroqol (EQ-5D-5L)		X										X	X				
Stroke and Aphasia Quality of Life (SAQoL)			X														
Walking ability																	
6-minute walk test (6MWT)							X				X			X	X		
10-meter walk test (10MWT)			X										X			X	
Balance																	
Berg Balance Scale (BBS)									X	X			X	X			
Timed Up and Go Test (TUG)		X						X	X		X						
Activities-Specific Balance Confidence Scale (ABC)																X	
Activities of daily living and independence																	
Barthel Index (BI)	X				X	X								X			
Frenchay Activities Index (FAI)					X			X									
EQ-Visual analogue Scale (EQ VAS)					X												
Functional Independence Measure (FIM)							X										
Instrumental Activities of Daily Living Questionnaire (IADLq)							X			X							
Impairments																	
Rivermead Mobility Index (RMI)		X						X					X				
Elderly Mobility Scale (EMS)										X							

modified Patient-Specific Functional Scale (modified PSFS)		X													
Motricity Index						X							X		
Mini-Mental State Examination													X		
Fatigue Assessment Scale (FAS)		X	X												
Short Physical Performance Battery (SPPB)													X		X
Social participation															
Hospital Anxiety and Depression (HAD)				X				X							
Patient Health Questionnaire (PHQ)			X												
Hamilton Rating Scale (HRS)													X		
Geriatric Depression Scale (GDS)	X						X				X				
Subjective Index of Physical and Social Outcome (SIPSO)								X							
Activity Card Sort (ACS)							X								
Life-Satisfaction questionnaire (Li-Sat)							X								
Exercise Beliefs and Exercise Self-Efficacy questionnaires (EBESE)		X													
Carer strain : Caregiver Strain Index (CSI)	X				X			X					X		

Quantitative Analysis

Figure 4 shows the overall effect of the experimental interventions on the three outcomes (quality of life, walking capacity, and balance) compared to other rehabilitative strategies (institution-based rehabilitation). Figure 4 also displays the subgroup analyses regarding the three outcomes.

The overall analysis showed a significant difference effect in favour of CBR interventions compared to other rehabilitative strategies (SMD=0.22[0.07, 0.37], P=0.004, I²=77%).

Figure 4: Overall and subgroup analyses of the effect of CBR interventions on quality of life, walking capacity, and balance.

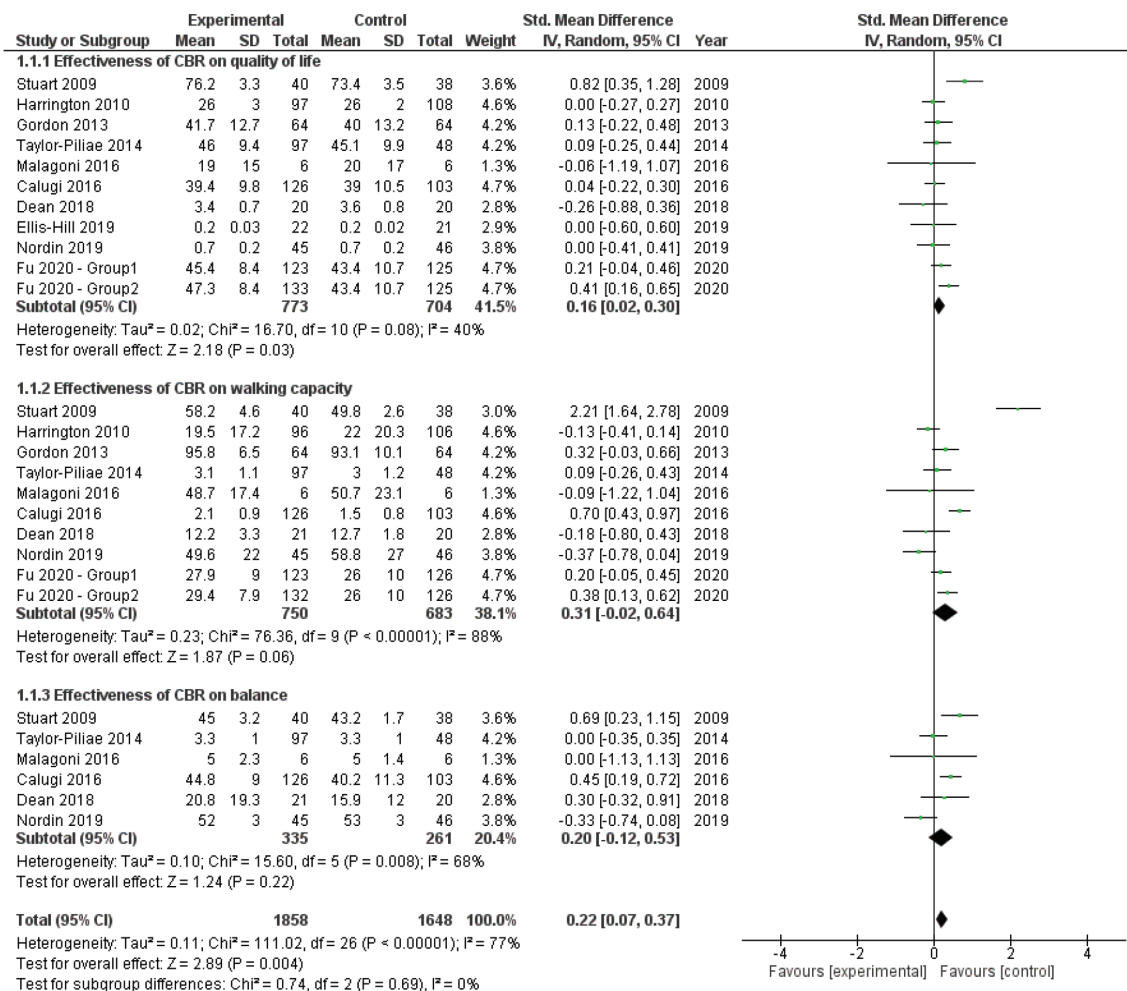


Figure legend: Forest plot showing overall and subgroup analyses of the effect of CBR interventions on quality of life, walking capacity, and balance. The effects are shown by the standard mean difference (SMD); significance set at $p < 0.05$

Subgroup Analysis

- Ten trials with 11 experimental (773 participants) and control (704 participants) groups described the effect of CBR on QoL. Significant effects were found in favour of CBR (SMD=0.16[0.02, 0.30], $P=0.03$, $I^2=77\%$).
- Nine trials with 10 experimental (750 participants) and control (683 participants) groups described the effect of CBR on walking capacity. Results shows similar effects of CBR compared with other rehabilitative strategies (SMD=0.31[-0.02, 0.64], $P=0.06$, $I^2=88\%$).
- Six trials with 6 experimental (335 participants) and control (261 participants) groups described the effect of CBR on balance. Results shows similar effects of CBR compared with other rehabilitative strategies (SMD=0.20[-0.12, 0.53], $P=0.22$, $I^2=68\%$).

DISCUSSION

The purpose of this systematic review and meta-analysis was to evaluate the efficacy of CBR on quality of life in people post stroke compared to institution-based rehabilitation (IBR) or no care. Secondary objectives included reviewing the content of CBR and evaluating its effect on balance and walking capacity in people post stroke. Results showed that CBR interventions were more effective on QoL for people with chronic stroke compared to institution-based rehabilitation or no care. Also, CBR interventions were as effective as institution-based rehabilitation or no care in improvement of walking capacity and balance.

These results suggest that people treated in community settings obtain better QoL outcomes than those who received institution-based rehabilitation or no care. This conclusion applies to chronic people post stroke, as only one (Fu et al, 2020) out of 16 studies report on the subacute phase of stroke (1.5 months after stroke). Evidence from a previous meta-analysis also suggests that CBR is significantly more effective in improving QoL at three months for the physical activity area of the SF-36 instrument (Naidoo, 2010). Even though favourable roles for rehabilitation in people with chronic stroke are now reported (Maguire et al, 2012; Morreale et al, 2016; Korkmaz et al, 2021), evidence suggests that best results usually occur within the first few weeks and months after stroke (Jørgensen et al,

1995; Morreale et al, 2016).

Benefits associated with home and community rehabilitation lie in the fact that the environment is familiar to the person, it provides emotional security, the client is the focus of the treatment programme, and goal setting is more relevant (Eldar, 2000; Kendall et al, 2007). The involvement of the family and the community in the care system would have a favourable impact on the quality of life of clients and therefore on their recovery. Upon closer inspection, this review found 2 studies (Stuart et al, 2009; Fu et al, 2020) with strong significance for the effectiveness of CBR on QoL. The study by Stuart et al (2009) which revealed a strong positive effect compared a CBR intervention with usual care, without the physical training component. For the study of Fu et al (2020) (group 2), a significant effect was found by comparing CBR to written educational material about stroke, covering common issues following stroke and risk factor management. The common factor of the last two mentioned studies was the total number of sessions (duration) of the selected programmes. Fu et al (2020) (group 2) involved the 'Taking Charge' programme for 48 weeks (twice per week) while Stuart et al (2009) performed an intervention that lasted 24 weeks (3 times per week).

The overall effect from the meta-analysis indicates that CBR had an effect (non-significant) on walking capacity and balance. This effect can be understood from the positive relationship reported between balance and functional independence in people post stroke (Langhammer et al, 2008; Kossi et al, 2019; Nindorera et al, 2021). Moreover, previous studies have identified the predictive value of specific types of scales on activities of daily living (walking) after a stroke (Naidoo, 2010; Fu et al., 2020). However, in one review (Naidoo, 2010) it was indicated that CBR had no significant effect on functional independence as measured with the Barthel Index score.

A wide variety of aspects of CBR were noted in the studies included in the present systematic review: adaptive physical activity, walking, tai chi, community-based exercise programme or home-based programme, etc. This variety was expected since CBR is a strategy that is based on the needs of *people living with disabilities* (Khasnabis & Motsch, 2008; Madden et al., 2014). This evidence should be used in the context of international frameworks such as the WHO CBR Matrix or the WHO rehabilitation services framework. It is important to note that the identified CBR components are relevant for the optimal integration, activation and participation of stroke survivors in the community.

Other factors to consider when interpreting the results of this review include variations in the interventions between comparison groups and the relatively small number of studies included in the data analysis. Intervention outcomes emphasised change in the physical component of health-related QoL and in the mental component as well. Consequently, the study results collectively were mixed or hybrid interventions, with several studies reporting statistically significant improvements in groups receiving interventions compared with control groups.

The methodological quality of the included studies was considered good. Common methodological weaknesses in these studies included the lack of blinding of therapists and clients (Siu et al, 2009). While acknowledging that it is not always possible to blind participants in CBR intervention studies, given that all of the studies used blinding of the assessor reduces the potential for evaluation bias (Siu et al, 2009). Therefore, the authors feel that bias on the part of the outcome assessment has been negated. Granted that the lack of blinding has the potential to increase community-based participants' motivation to try to obtain compensatory treatment or put more effort into self-management to compensate their potential loss of the institution-based treatment (Siu et al, 2009).

Strength and Limitations

This review focused on 16 studies with 10 RCTs included in the meta-analysis. RCTs and clinical trials are universally considered to be the "gold standard" designs providing strong evidence for guiding practice and to examine causal relationships between rehabilitation interventions and outcomes. The studies included in this review provided sufficient data to understand the components and recommendations regarding the use of CBR to improve quality of life, walking and balance in people with chronic stroke. Nonetheless, the findings need to be interpreted in the context of potential limitations. First, the search was restricted to studies published in English or French, and relevant studies in other languages may have been missed. Secondly, QoL is a complex construct and no distinction was made between general measures of QoL and those that were considered to be related to health.

CONCLUSION

This systematic review and meta-analysis aimed to review the content of community-based rehabilitation (CBR) and to compare its effectiveness with other

rehabilitative strategies. The results showed that CBR interventions can be used in many forms to improve QoL, walking capacity, and balance in people with chronic stroke. In low- and middle-income countries, where human resources for rehabilitation are very limited, it is clear that developing cost-effective models of rehabilitation care is fundamental for stroke survivors. Evidence from this review suggests that self-directed rehabilitations interventions could constitute a promising strategy for people with chronic stroke.

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A Rapid Review of the Roles of Community Rehabilitation Workers in Community-based Mental Health Services in Low- and Middle-Income Countries

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ABSTRACT

Purpose: *The term Community Rehabilitation Worker (CRW) encompasses a group of mid-level health workers introduced within healthcare systems to increase accessibility to health-care services for individuals within the community sphere. This study aimed to summarise the current knowledge on the role of community rehabilitation workers in community-based mental health services in low- and middle- income countries.*

Method: *Between the 10th and 17th of July, 2020, searches were conducted on the following databases: Cochrane, EbscoHost, Primo, and Pubmed. The search strategy identified 521 individual records, 4 of which were included in this review: 2 qualitative descriptive studies, 1 quantitative descriptive study and 1 conceptual study.*

Results: *Across the 4 studies, eight roles of community rehabilitation workers were identified in relation to mental health services: home visits, client illness management, referral, documentation and administration, client and family education, community education, intersectoral collaboration and mediation. There was no data found on the role of community rehabilitation workers in mental health services in low- and middle- income countries specifically, indicating a gap in research.*

Conclusion: *There is a need to improve knowledge and understanding of the roles and responsibilities of community rehabilitation workers where mental health service provision is concerned. The data summarised in this review could be utilised to educate health professionals regarding the role of community rehabilitation workers.*

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Key words: community rehabilitation workers, mental health services, roles, community-based, low- and middle-income countries

INTRODUCTION

Approximately 85% of the world's population resides in low- and middle-income countries (World Bank, 2020). These populations tend to face challenges with regard to provision of healthcare, especially that of mental health services. South Africa is considered to be a middle-income country (World Bank, 2020). Middle-income countries are those with a gross national income (GNI) between \$1 036 and \$12 535, whilst low-income countries are countries with a GNI of \$1 035 or less (World Bank, 2020). Although low-income countries and middle-income countries have differing GNIs, they both face the challenge of a high burden of disease due to mental illness (Rathod et al., 2017; World Bank, 2020). The burden of mental illness is a result of social factors such as poverty, famine, urbanisation, internal migration and crime (Allen et al., 2014). These are prevalent stressors that perpetuate the cycle of inequities in low- and middle-income countries.

Global economic recession has placed increasing pressure and limitations on government budgets, which are the main source of funding for public healthcare systems in low- and middle-income countries (Basu et al., 2012). Funding available to address mental illness in these countries is minimal due to already tight budgets being prioritised for the provision of somatic health services, both in public and private healthcare systems (Chisholm et al., 2007). The prioritisation of somatic health services has resulted in accessibility constraints in relation to mental health services for the majority of the populations in low- and middle-income countries utilising public healthcare systems (Chisholm et al., 2007). This results in a mismatch between the increasing need for mental health services and the persistent scarcity of resources in the form of finances, workforce and infrastructure allocated to mental health services (Rathod et al., 2017). There is a notably large treatment gap between those that require mental health services and those who receive these services in low- and middle-income countries (Wright and Chiwandira, 2016). This gap exacerbates the ongoing global burden of disability (Shidhaye et al., 2016). Furthermore, the mental healthcare services that are available are generally focused within tertiary psychiatric hospitals rather than at the primary healthcare level (Jack et al., 2014). This realisation has led to a growing international agreement that decreasing the treatment gap in low- and middle-income countries requires a task-shifting or task-sharing approach

and integration of mental health care into primary care (Lund et al., 2015). A task-shifting approach makes use of non-specialists/general health workers, such as Community Rehabilitation Workers (CRWs), who have been given mental healthcare training, to deliver mental health services within communities (Lund et al., 2015).

The concept of community rehabilitation workers dates back to 1957 (Lehmann and Sanders, 2007). Community rehabilitation workers are community-based rehabilitation (CBR) personnel who were first introduced in South Africa (SA) in 1986 to aid with the provision of CBR (CREATE,2015). The healthcare support personnel initially received foundational training. Thereafter, they were specifically trained as community rehabilitation workers to address, among other aspects, the basic health needs of persons with disabilities within both the somatic and mental health domains in rural communities of South Africa (Petrick et al., 2002).

Community rehabilitation workers are community-based public health workers who receive foundational training aimed at addressing the quality of life of communities (Lehmann and Sanders, 2007). The community rehabilitation workers' cadre is fundamental to the provision of primary health care (PHC), as community rehabilitation workers increase the accessibility of healthcare services for individuals within the communities they serve (Lehmann and Sanders, 2007). Pallas et al. (2013) go on to stress that the role of community rehabilitation workers in the provision of primary health care is valuable in the context of low- and middle- income countries.

The advantages of recognising community rehabilitation workers in a task-shifting approach include: improved accessibility to care and health education and a reduction in stigma surrounding mental illness in communities (Lund et al., 2015). Unfortunately, there is limited knowledge on, and understanding of, the role of community rehabilitation workers, particularly in the scope of mental healthcare provision (Stacciarini et al., 2012). Thus, it is possible that with an increase in knowledge of the role of community rehabilitation workers the aforementioned advantages could be realised.

Objective

This rapid review aims to provide a summary of the current available knowledge regarding the role of community rehabilitation workers within community-based

mental health services in low- and middle- income countries. This review could inform students in healthcare, staff that train community rehabilitation workers and health professionals on the role of community rehabilitation workers. Clarifying the role and contribution of community rehabilitation workers within this review, could help to promote further investment of resources and interest in the area of CBR and the community rehabilitation workers who are tasked with delivering this care. A holistic understanding of the role of community rehabilitation workers in mental health services may inspire better collaboration between the various sectors to better serve the population in need. This review will also be appropriate within the South African context; its focus within low- and middle-income countries will help to inform mental healthcare provision in South Africa.

The research question therefore is:

What are the roles of community rehabilitation workers in community-based mental health services in low- and middle- income countries?

METHOD

Study Design

Rapid review was used as a form of knowledge synthesis, where systematic review processes were utilised in a streamlined manner. Reviews utilise systematic analysis and critical appraisal which greatly reduce bias (Hoffmann et al., 2013; Tricco et al. and World Health Organisation, 2017). Rapid reviews are used as a practical approach to provide actionable and relevant current evidence as well as identify research gaps that can be targeted in future (Tricco et al. and World Health Organisation, 2017).

Search Strategy

The reviewers conducted the search between July 10th and July 17th, 2020. The search was conducted on the following multidisciplinary medical and public health databases: Cochrane, EbscoHost (CINHAL, AFRICA WIDE, MEDLINE), Primo, and Pubmed. The databases were searched using the following keywords: "Role" AND "Community-based Services" OR "Community-based Rehabilitation" AND "Community Rehabilitation Workers" OR "Community Rehabilitation Facilitators" OR "Community-based Disability Workers" OR

“Community Health Workers” OR “Village Health Workers” AND “Mental Health Services” OR “Mental Health Care” OR “Psychiatric Services”.

Study Selection

The process began by ensuring that any duplicate articles of the initial search results were removed. Search results were then screened according to the selection criteria, with the intention of erring on the side of inclusion where there was doubt of a study’s status. This ensured that no potentially relevant pieces of research were prematurely excluded. The initial stage of screening excluded sources based upon dates, language, country and data type. The next stages of screening involved exclusions based upon title, and then abstract screening. The inclusion criteria were then once again applied to the full texts of the studies, to conclude screening and finalise the selection process (see Table 1).

Table 1: Inclusion and Exclusion Criteria

Inclusion	Exclusion
Time frame: Articles published within the last 20 years	
Articles only from low- and middle-income countries. *See list of countries (World Bank, 2020) in Appendix A	
Publication/data types to be included: peer-reviewed academic articles	Publication type to be excluded: grey literature such as opinion pieces, conference papers, government reports, policy statements, dissertations and pamphlets
Articles that have one of the key terms: community rehabilitation workers (or community-based disability workers or community health workers or community rehabilitation facilitators or village health workers) and mental health services (or mental health care or psychiatric services) in the title	Duplicate articles from the same study
The review will be limited to full text articles written in English, or readily available in an English translation	
Quantitative and qualitative research articles	

Screening Process

After the screening of the full texts, the articles that remained were then critically discussed and evaluated with an external reviewer acting in a supervisory

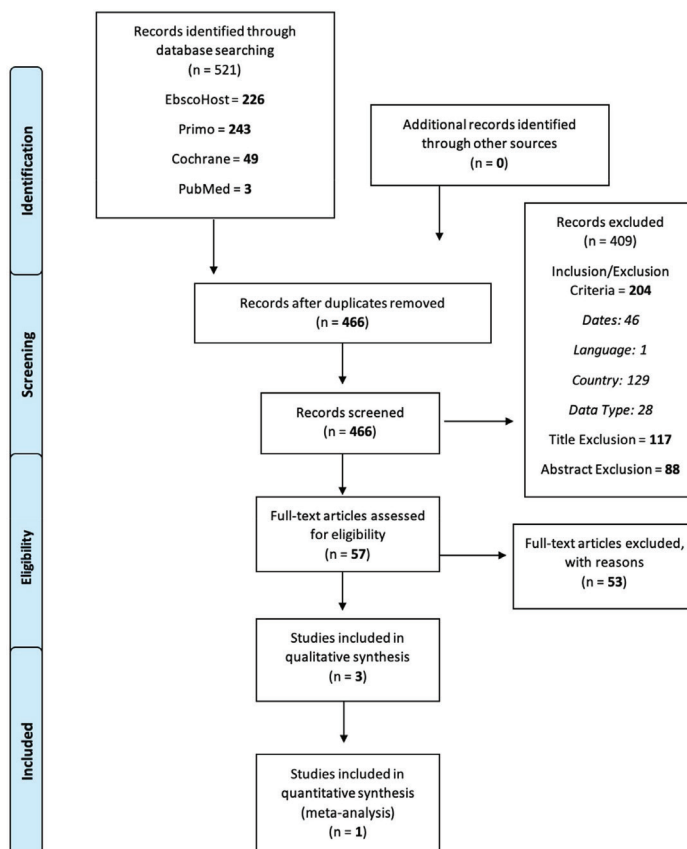
position. Following this consultation, additional articles were excluded based upon their appropriateness to the topic of the review. This resulted in the final selection of four articles.

Types of Studies

Systematic reviews were prioritised for inclusion, as these can provide extensive information pertaining to the research topic. Additionally, both qualitative and quantitative studies have been included in the review. Study designs positioned higher up in the hierarchy of evidence have more rigorous methodology, which can minimise the effect of bias on the results of the study (Hoffmann et al., 2013).

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses statement (PRISMA) flow chart was used by the reviewers to track article inclusions and exclusions (see Figure 1).

Figure 1: PRISMA 2009 Flow Diagram



Data Extraction

The data extraction process aimed to highlight the critical information from each included study that was most relevant to the topic of the review. In this rapid review, data extraction was undertaken by a group of six reviewers using a data extraction form. The data extraction form was developed by the reviewers to include the following criteria: author, date, country, aim, methodology, population, specific roles of community rehabilitation workers, and level of evidence of each study. The pertinent information was then utilised in analysis and evidence synthesis.

Four reviewers, working in pairs, were tasked with extracting relevant information from the four chosen articles, with each pair extracting data from two articles, respectively. The remaining two reviewers were responsible for overseeing this process and ensuring consistency in the approach to data extraction. These two reviewers were required to critically examine all four articles to ensure no pertinent information was neglected during the data extraction process. The purpose of the two reviewers overseeing the data extraction process was to ensure confirmability and neutrality of extracted data and prevent any oversight of information (Ghafouri and Ofoghi, 2016). Any disagreements that occurred between reviewers during the data extraction process would be resolved through discussion and consensus between the six reviewers. When no consensus was possible, an external reviewer acted in a supervisory position by addressing any disagreement and facilitating resolution of the issue. This seventh person was also the corresponding author for this review.

Assessment of Methodological Quality

The methodological quality of the four included studies was assessed by all six reviewers. The quantitative study and the shortest qualitative study were each assessed by one reviewer respectively (two reviewers). Each of the two more extensive qualitative studies was assessed by a pair of reviewers respectively (four reviewers). Within each pair, the two reviewers worked separately to assess the same longer article and then combined their assessments to formulate one final critical appraisal for each study. The Critical Appraisals Skills Programme (CASP) was used to assess the studies. The use of appraisal tools was a means of standardisation across the four separate studies to ensure correlation of the papers in relation to the research question.

To minimise any systematic errors or deviations from the truth, the reviewers utilised several strategies to mitigate risk bias (Viswanathan et al., 2017). All six reviewers were involved in data extraction, critically appraised sources, and compiled findings together. This was done with the intention to enhance the confirmability of this review and subsequently reduce the risk of bias (Ghafouri and Ofoghi, 2016). Secondly, the reviewers engaged in reflection and documentation of all processes undertaken during the review, to ensure all decisions were taken note of and the review process was appropriately tracked in detail. This also ensured that the reviewers were held accountable to their own biases and how this may have influenced the review findings. Reflexive analysis is a beneficial tool to minimise risk of bias and ensure researchers are aware of their own influence on the data findings (Ghafouri and Ofoghi, 2016).

The CASP was used as a means of appraising the quality of each source. Particular focus was placed upon question 6 in the CASP for qualitative research - "Has the relationship between the researcher and participants been adequately considered?" - in order to note the influence of any bias held by the researchers, as well as potential influences they may have had on the results of the study. Additionally, the reviewers considered the extent to which the authors of each article analysed and documented their methodology and data analysis process, to further analyse potential risk of bias.

The reviewers utilised a hierarchy of evidence to finalise selection of studies according to their position on the hierarchy, with the intent of prioritising studies found higher up on the hierarchy where this was possible. Studies higher up in the hierarchy of evidence generally have a more rigorous methodology, which can minimise the risk of bias (Hoffmann et al, 2013).

Data Analysis - Synthesis of Results

The process of data analysis focused on making sense of the critical information extracted from each article using a data extraction form created by the reviewers. A content analysis of the roles of community rehabilitation workers from each article was performed through the systematic classification of coding and identifying themes within the data (Abdulkareem et al., 2018). A detailed, in-depth analysis of the themes and categories of the roles and functions was used to provide a rich description of the roles of community rehabilitation workers. Once these themes were summarised, the evidence was then organised to formulate a discussion and draw conclusions.

RESULTS

Literature Search

The reviewers conducted the search between July 10th and July 17th, 2020. The search was conducted on the following multidisciplinary medical and public health databases: Cochrane, EbscoHost (CINHAL, AFRICA WIDE, MEDLINE), Primo, and Pubmed. The databases were searched using the following keywords: “Role” AND “Community-based Services” OR “Community-based Rehabilitation” AND “Community Rehabilitation Workers” OR “Community Rehabilitation Facilitators” OR “Community-based Disability Workers” OR “Community Health Workers” OR “Village Health Workers” AND “Mental Health Services” OR “Mental Health Care” OR “Psychiatric Services”.

Study Selection

The initial search yielded a total of 521 articles. Duplicates were removed, leaving the article count at 466. The articles’ titles and abstracts were then screened utilising the inclusion and exclusion criteria, which left a total of 57 articles. The full texts of the remaining 57 articles were then read and assessed for eligibility based upon each study’s relevance to the research question. This resulted in 4 articles being included in the rapid review.

Table 2 below illustrates the characteristics of the studies that were included (Binken et al., 2009; Como and Batdulam, 2012; Chebolu-Subramanian et al., 2019; Ortega and Wenceslau, 2020). All four of the countries in which the studies were based are middle-income countries; thus none of these studies represent low-income countries (World Bank, 2020).

Table 2: Characteristics of Included Studies

Author (year)	Country & World Bank Classification	Title	Study Design	Roles Identified
Binken and Miller (2009)	South Africa	The value of the service offered by the community rehabilitation worker	Qualitative descriptive study	1. Direct client contact 2. Community education 3. Intersectoral collaboration 4. Not otherwise specified

Chebolu-Subramanian et al. (2019)	India	A time motion study of community mental health workers in rural India	Quantitative descriptive study	<ol style="list-style-type: none"> 1. Identifying clients with priority mental health disorders 2. Counselling and following-up of identified clients 3. Conducting awareness meetings in the community 4. Screening clients 5. Coordinating with family members of identified clients 6. Referral of clients 7. Documentation and reporting of all activities.
Como and Batdulam (2012)	Mongolia	The role of community health workers in the Mongolian CBR programme	Qualitative descriptive study	<p>PHC activity roles:</p> <ol style="list-style-type: none"> 1. Health promotion and prevention 2. Early identification of health conditions 3. Primary and emergency care 4. Referral to higher level facilities <p>Various social roles which include:</p> <ol style="list-style-type: none"> 5. Involvement in social development projects 6. Disability awareness 7. Advocacy for the rights and social inclusion of people with disabilities <p>Role linked to the livelihood domain of the CBR matrix:</p> <ol style="list-style-type: none"> 8. Helping persons with disabilities to access disability grants and pension
Ortega and Wenceslau (2020)	Brazil	Challenges for implementing a global mental health agenda in Brazil: The "silencing" of culture	Conceptual study	<ol style="list-style-type: none"> 1. Provide PHC services 2. Mediators

Risk of Bias

All studies remaining after screening according to the inclusion and exclusion criteria were classified as descriptive studies (level III) (Ackley et al., 2008).

Como and Batdulam's article (2012) indicated a high risk of bias. In addition to the researchers not considering the relationship between themselves and the participants, the authors did not reflect on how their own roles or potential personal biases may have influenced the study design and results. The study's

ethical considerations were also not sufficiently reported on, which attaches further bias to the study.

Articles by Binken and Miller (2009) and Ortega and Wenceslau (2020) indicated a moderate risk of bias. According to the CASP, these articles did not adequately explore the relationship between the researchers and participants.

The article by Chebolu-Subramanian et al. (2019) was of a low risk of bias. The study's data was collected by an observer external to the organisation involved in the study (the Foundation for Research in Community Health) to neutralise any personal bias.

Synthesis of Results

Based on findings within the literature, it was identified that community rehabilitation workers occupy several roles in the provision of mental health services in low- and middle- income countries. They are involved in home visits, client illness management, referral, documentation and administration, client and family education, community education, intersectoral collaboration, and cultural mediation. The findings are summarised below.

Home Visits

All the four included articles refer to home visits as one of the roles of community rehabilitation workers (Binken et al., 2009; Como and Batdulam, 2012; Chebolu-Subramanian et al., 2019; Ortega and Wenceslau, 2020).

Binken et al. (2009) highlighted the importance of home visits as a means of improving accessibility to healthcare services. The authors elaborated that by community rehabilitation workers facilitating care at home, there is a greater likelihood of successful rehabilitation that is contextually appropriate.

Client Illness Management

Community rehabilitation workers are responsible for the implementation of PHC activities at a community level, including early identification of health conditions, health promotion and disease prevention, as well as primary and emergency care (Como and Batdulam, 2012). The community rehabilitation workers' primary care services included counselling services and other forms of psychosocial support (Como and Batdulam, 2012; Chebolu-Subramanian et al., 2019). The provision of psychosocial support aids in the improvement of the client's confidence and

ability to participate more actively within the community, as well as for the prevention of worsening of illness or fatality (Como and Batdulam, 2012). Two articles (Como and Batdulam, 2012; Chebolu-Subramanian et al., 2019) reported that community rehabilitation workers are also responsible for screening of at-risk clients in the community which included prioritising those with mental health disorders.

Referral

Three of the four included studies highlight the important role of referral by the community rehabilitation workers (Binken et al., 2009; Como and Batdulam, 2012; Chebolu-Subramanian et al., 2019).

Como and Batdulam (2012) reported that community rehabilitation workers make referrals of people with disabilities to specialist health services and they coordinate with the appropriate health specialists to organise the needed consultations. Additionally, Como and Batdulam (2012) stated that community rehabilitation workers refer people with disabilities to the appropriate social and welfare services, to facilitate the provision of additional support for people with disabilities.

Documentation and Administration

Three of the four included studies indicated that community rehabilitation workers engage in the role of documentation and administration (Binken et al., 2009; Como and Batdulam, 2012; Chebolu-Subramanian et al., 2019).

Chebolu-Subramanian et al. (2019) stated that community rehabilitation workers spend a significant amount of their time on documentation and administration tasks, which they refer to as “non-value added but necessary activities”. This was echoed by Binken et al. (2009) who reported that documentation and administration activities occupy a large portion of community rehabilitation workers’ work day. Documentation in a prescribed format supports and allows for efficiency in, and coordination of, their community and client-centred activities and interventions (Chebolu-Subramanian et al., 2019). The type of documentation used included client record sheets, work activity record sheets and lists of the resources to which the community rehabilitation workers referred their client (Binken et al., 2009).

Client and Family Education

Three of the four included studies mentioned client and family education as major roles of community rehabilitation workers (Binken et al., 2009; Como and Batdulam, 2012; Ortega and Wenceslau, 2020). Psychoeducation is usually facilitated during regular visits to the clients' homes (Ortega and Wenceslau, 2020). Psychoeducation allows for the enhancement of the clients' knowledge and skills pertaining to management of their mental illness within the context of their home and community, thus improving their capacity for independence (Binken et al., 2009). In terms of provision of education, community rehabilitation workers assist the family in gaining insight into the nature of the mental illness of people with disabilities and how the illness influences behaviour (Binken et al., 2009; Ortega and Wenceslau, 2020). This results in developing better coping skills for the clients and caregivers or family.

Community Education

All four included studies indicated that community rehabilitation workers utilise community spaces to promote the integration and inclusion of people with disabilities through community activities. They conduct community education by means of community-orientated education meetings and initiatives (Binken et al., 2009; Como and Batdulam, 2012; Chebolu-Subramanian et al., 2019; Ortega and Wenceslau, 2020). Education meetings were intended to raise awareness about disability and encourage community members to become involved in community-based rehabilitation initiatives, including health promotion, disease prevention and stigma reduction in relation to mental illness (Como and Batdulam, 2012). The concept of advocacy for the rights related to social inclusion and empowerment of people with disabilities within the forum of community meetings, was stressed (Binken et al., 2009; Ortega and Wenceslau, 2020). These authors suggest that the promotion of the rights of people with disabilities and integration of these individuals into the community is facilitated by addressing the community members' predetermined attitudes toward disability and mental illness (Binken et al., 2009).

Intersectoral Collaboration

Two of the four included studies noted that community rehabilitation workers are involved in intersectoral collaboration where they make links with other sectors, government departments and health structures (Binken et al., 2009; Como and

Batdulam, 2012). Common needs identified in a middle-income country include: financial security, safe housing, income-generating jobs and family support (Binken et al., 2009). Community rehabilitation workers need to collaborate with government departments and special services as they alone cannot address the above-mentioned needs (Binken et al., 2009). The sectors/services involved in this collaboration may include the governmental departments of social development, social welfare, financial services, labour and housing. Community rehabilitation workers are also responsible for collaborating with local government to collect and update demographic and socioeconomic data of the local community that is then provided to the department of health for government reporting, thus facilitating the monitoring of the local population's health indicators (Como and Batdulam, 2012).

Mediation

Two of the four included studies identified cultural mediation as an important role that community rehabilitation workers fulfil ((Binken et al., 2009; Ortega and Wenceslau, 2020). While Binken et al. (2009) noted mediation as a role of community rehabilitation workers, Ortega and Wenceslau (2020) outlined the importance of cultural competency as part of mediation in the work of community rehabilitation workers. Community rehabilitation workers utilise their cultural competency to take on the role of mediators between their community's beliefs and lifestyles and their own professional knowledge of scientific and medical practices within mental health (Ortega and Wenceslau, 2020). Community rehabilitation workers are described as social actors who have an in-depth understanding of local cultural idioms including beliefs, traditions, values and habits of the members of the community (Ortega and Wenceslau, 2020). Community rehabilitation workers mediate between traditional world views and biomedical treatment principles (Ortega and Wenceslau, 2020).

DISCUSSION

Summary of Evidence

In the four articles that were examined, there was some overlap in the various studies' discussions of the roles and functions that community rehabilitation workers engage in. Unfortunately, many articles that were screened for use within this review had to be excluded, due to the fact that many discussed

the 'ideal' role/practice of community rehabilitation workers in mental health services, and not the current reality of their practice. Within the four included studies it was discovered that there are many different forms of training and roles of community rehabilitation workers that are very specific to each country and/or distinct community. These differences appear to be why it is difficult to distinctly define a universal role of community rehabilitation workers in mental health services at a community level.

It became apparent during the data collection process that there is significantly more available information pertaining to the roles community rehabilitation workers play in somatic health than in mental health. A significant number of articles collected and screened during study selection had to be excluded from the review, as they covered community rehabilitation workers' roles solely in the provision of somatic health care. Only the four studies summarised in this review analysed their role within mental health care.

Analysis of the research findings suggested that community rehabilitation workers have significant potential to reduce the treatment gap in mental health services in low- and middle- income countries (Chebolu-Subramanian et al., 2019). With the concept of task-shifting, multidisciplinary teams would be able to collaborate with community rehabilitation workers to improve accessibility to mental health services in low- and middle- income countries (Chebolu-Subramanian et al., 2019).

During data synthesis, it was discovered that although the methodology included both low-income countries and middle-income countries, all of the included studies originated from middle-income countries (Mongolia, India, South Africa and Brazil). This reveals a gap in the research, as low-income countries are vastly under-represented. Therefore, the reviewers were able to summarise the roles of community rehabilitation workers in community-based mental health services in low- and middle-income countries, and not in both middle-income countries and low-income countries as originally planned.

It is suggested that collaboration between the multidisciplinary team and community rehabilitation workers will enable the latter to take on tasks such as basic preliminary screening, psychoeducation and follow-up care within the communities. Collaboration would also ease the burden on the health department, by ensuring that those who have been discharged from specialist mental healthcare facilities receive continuity of care and consistent illness

management at a community level. The aspiration is that if the hospital-based multidisciplinary team collaborates effectively with community rehabilitation workers, their role in continued community-based care will help to minimise pressure on health care and increase intersectoral collaboration.

Limitations

During the screening process only four articles were deemed relevant to the review; this resulted in a limited pool of information from which to make deductions and comparisons.

There were no included studies from low-income countries as all four selected articles were conducted in low- and middle-income countries. This lack of information pertaining to the role of community rehabilitation workers in mental health services in low- and middle-income countries resulted in a gap in the findings. Also, all articles written in languages other than English were not included. Therefore, it is possible that relevant articles were overlooked on the basis of language.

CONCLUSION

A total of eight roles that community rehabilitation workers have in relation to mental health services in low- and middle-income countries were identified. These roles are home visits, client illness management, referral, documentation and administration, client and family education, community education, intersectoral collaboration, and cultural mediation. However, there was no data found on the role of community rehabilitation workers in mental health services in low- and middle-income countries, indicating a significant research gap. Therefore, the reviewers would recommend further research to be conducted on community rehabilitation workers' role in mental health services in low- and middle-income countries. The data summarised in this review could be utilised to educate health professionals regarding the role of community rehabilitation workers. If their roles were better understood, community rehabilitation workers would have the potential to ease the current burden on health departments and improve accessibility to mental health services for those living within rural communities. The information could also be employed by teaching facilities that cover the training of community rehabilitation workers to provide evidence on the role of the community rehabilitation worker in mental health services. This would ensure better awareness and use of the services of community health workers,

and subsequently improve collaboration between the formalised health sectors and them.

Declaration of No Conflicting Interest

The authors report no conflict of interest.

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Appendix A

List of Low- and Middle-Income Countries (World Bank, 2020)

Low-Income Countries

Afghanistan	Guinea-Bissau	Sierra Leone
Burkina Faso	Haiti	Somalia
Burundi	Korea, Dem. People's Rep.	South Sudan
Central African Republic	Liberia	Sudan
Chad	Madagascar	Syrian Arab Republic
Congo, Dem. Rep	Malawi	Tajikistan
Eritrea	Mali	Togo
Ethiopia	Mozambique	Uganda
Gambia, The	Niger	Yemen, Rep.
Guinea	Rwanda	

Middle-Income Countries

Angola	Honduras	Papua New Guinea
Algeria	India	Philippines
Bangladesh	Kenya	São Tomé and Príncipe
Benin	Kiribati	Senegal
Bhutan	Kyrgyz Republic	Solomon Islands
Bolivia	Lao PDR	Sri Lanka
Cabo Verde	Lesotho	Tanzania
Cambodia	Mauritania	Timor-Leste
Cameroon	Micronesia, Fed. Sts.	Tunisia
Comoros	Moldova	Ukraine
Congo, Rep.	Mongolia	Uzbekistan
Côte d'Ivoire	Morocco	Vanuatu
Djibouti	Myanmar	Vietnam
Egypt, Arab Rep.	Nepal	West Bank and Gaza
El Salvador	Nicaragua	Zambia
Eswatini	Nigeria	Zimbabwe
Ghana	Pakistan	
Albania	Fiji	Montenegro
American Samoa	Gabon	Namibia
Argentina	Georgia	North Macedonia
Armenia	Grenada	Paraguay
Azerbaijan	Guatemala	Peru
Belarus	Guyana	Russian Federation

Belize	Indonesia	Samoa
Bosnia and Herzegovina	Iran, Islamic Rep.	Serbia
Botswana	Iraq	South Africa
Brazil	Jamaica	St. Lucia
Bulgaria	Jordan	St. Vincent and the Grenadines
China	Kazakhstan	Suriname
Colombia	Kosovo	Thailand
Costa Rica	Lebanon	Tonga
Cuba	Libya	Turkey
Dominica	Malaysia	Turkmenistan
Dominican Republic	Maldives	Tuvalu
Equatorial Guinea	Marshall Islands	Venezuela, RB
Ecuador	Mexico	

Integrating Traditional Bone-Setting and Orthopaedic Medicine Practices in the Management of Fractures in Nigeria: Community-Based Rehabilitation Model in Perspective

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ABSTRACT

Despite the documented advancements in orthodox medicine, traditional bonesetters (TBS) continue to be well patronised for the management of musculoskeletal injuries in low- and middle-income countries such as Nigeria. However, the practice of traditional bone-setting is often marred by the lack of trust and belief among orthodox healthcare practitioners on the one hand, and the serious post-fracture complications associated with this practice, on the other. The identified downsides have resulted in the stakeholders' call for the integration of TBS into the national orthodox healthcare services in Nigeria. Despite efforts toward the integration, implementation and realisation remain unfulfilled. One identified potential missing link is the lack of a community-oriented pathway such as the community-based rehabilitation (CBR) model in the previous efforts.

This brief review aims to elucidate the concept of CBR in relation to the proposed integration process. It highlights the need for integration, the notions of the CBR model as well as the conceptual framework for CBR. CBR has been showcased as a globally accepted model which encompasses pragmatic strategies or policies for community managers and stakeholders in a wide range of areas for people in need of essential services. It can be a suitable model for integrative management of fracture cases.

Key words: *community, traditional bone-setting, health systems, developing nations, integration, orthopaedic medicine*

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INTRODUCTION

Traditional medicine practice entails the adoption of alternative or non-conventional modes of care using herbs, animal and mineral substances, or other methods based on social, cultural, and religious principles that are peculiar to a particular community (Borokini & Lawal, 2014; Omoregie, Aliyu, Danjuma, & Folashade, 2015). Traditional medicine has been part of African culture from time immemorial and still enjoys patronage despite the remarkable advancements in orthodox medicine. In comparison with other selected African countries, it is estimated that about 86% of Nigerians use traditional medicine, and over 200,000 traditional medicine practitioners are believed to be in Nigeria (Adefolaju, 2014). The relative patronage of traditional medicine practitioners and their distributions per country are indicated in Table 1. The practice of traditional medicine is dependent on the background training and personal interest of an individual towards specific specialty areas. Among the practitioners in Nigeria, traditional bonesetters (TBS) are rated highest in terms of the patronage they receive across the strata of the Nigerian society (Dada, Yinusa & Giwa, 2011). According to the authors, about 85% of clients in need of fracture care are reported to have initial consultations with TBS. This was corroborated by another previous report that TBS provides about 70-90% of fracture care in some parts of Nigeria (Nwachukwu, Okwesili, Harris, & Katz, 2011).

Table 1: Country Distribution of Indigenous Traditional Medicine Providers and the Patronage (WHO, 2019)

Countries	Indigenous Traditional Medicine Providers	Patronage per Population (%)
Nigeria	200,000	70–86
Ghana	20, 000	60–79
Benin	7,500	80–99
South Africa	--	1–19
Senegal	1000	--
Cameroon	--	1–19
Cote d'Ivoire	20,000	80–99
Gabon	3000	80–99
Gambia	3000	--
Liberia	1500	60–79
Mali	5000	80–90

Despite the popularity of TBS in Nigeria, there are still issues with their perception, particularly among the orthodox medicine practitioners (OMPs), citing the vulnerability of clients under their care as a major concern. The perception is born out of the informal training that characterises the practice of TBS in fracture management. Anecdotally, clients with somewhat severe fractures who patronise TBS often end up with serious post-fracture complications including infection, e.g., osteomyelitis, delayed or non-union, heterotrophic ossification, avascular necrosis as well as extremity gangrene and, in some instances, death. Incidentally, the complications are usually brought to hospitals in a deplorable state. Moreover, the practice of TBS is somewhat shrouded in mystery, given the lack of clear-cut evaluation for definitive diagnoses which tends to favour practice without a clear-cut scope (Dada et al, 2011). Of more crucial concern is the lack of regulation and standardisation of TBS practice regarding fracture management, thus exposing clients to further risk of health complications. Contrarily, OMPs receive formal training in orthodox medicine and are certified by recognised universities, having met all requisite criteria. Suffice to state that, the practice of OMPs is supported by scientific principles informed by international standards and regulated by professional bodies. In view of the continuing popularity of TBS among their patrons (Chowdhury, Khandker, Ahsan & Mostafa, 2011; Aderibigbe, Agaja & Bamidele, 2013), the existing lack of integrative practice continues to undermine confidence, trust, safety, and optimal management outcomes. Although the clamour for such integration has received supports from various observers and commentators, the implementation is still laced with many challenges. A potential missing link yet to be explored is the role and position of TBS in a community-oriented programme such as community-based rehabilitation (CBR).

Community-based rehabilitation comprises measures taken at the community level to build on locally available resources within the community with the aim of providing beneficial service, while involving those who are in need, their families, and their community members (Samuel, 2015). The concept of CBR has however evolved over the years. The CBR system components encompass technology, service delivery, community involvement, and close cooperation with various organisations to support people with disabilities (Olaogun, Nyante & Bello, 2009; Seijas et al, 2018). The focus of CBR is partly geared towards enhancing the quality of life for people with disabilities and their families, meeting their basic needs, and ensuring inclusion and participation. The strength of CBR is premised on its principles of accessibility, equality, inclusiveness, and participation, thus representing the ideal approach to ensure the desired integrative healthcare

system. The aim of this short review is to demystify the concept of CBR as the facilitating agent for integrating the practices of TBS and OMP.

Community-Based Rehabilitation Notions

Community-based Rehabilitation (CBR) connotes the philosophy of empowerment of the people with disability in part through the active involvement of local communities. Traditional bonesetters are members of the community; hence they are important stakeholders. The basic concept of CBR is premised on the decentralisation of responsibility regarding service provision and mobilisation of human and financial resources to community level organisations (WHO in 1978, as cited in Samuel, 2015). A CBR programme is normally developed in response to one or more activities within one or a combination of the following five key components: education, employment, health, livelihood, and social services (Seijas et al, 2018). Healthcare provision is basic to members of the community; thus, harnessing the available resources within the community towards achieving the rehabilitation goal aptly defines the concept of CBR. According to Olaogun et al (2009), the two notions of CBR must guarantee:

1. A broad-based transfer of knowledge and skills in the rehabilitation of people with disabilities to their families and members of the community, in order to ensure the availability of rehabilitation to those in need.
2. An attitudinal change among healthcare providers by conceding that clients and people with disability have equal rights and privileges in the community.

In line with the above notions, since TBS bonesetters are important stakeholders in the provision of healthcare in the community, their integration into mainstream orthodox health care, through CBR, could be seen as a passage to boost healthcare accessibility at the community level. Hence, there is a need to form a progressive partnership with orthodox OMPs practitioners towards empowering community members, including TBS bonesetters, on healthcare-seeking agenda, and for the attainment of quality healthcare at personal and societal levels.

The Need for Integration

Orthopaedic surgeons/physicians are often sceptical about the mode of practice of TBS, given the informal way of receiving training and acquiring skills by the latter, coupled with the lack of documentation and regulation (Dada et al, 2011). The indiscernible forms of training has implications for serious post-fracture

complications arising from complex fractures (OlaOlorun, Oladiran & Adeniran, 2001; Nwadiaro, Nwadiaro, Kidmas, & Ozoilo, 2006). On the other hand, TBS bonesetters are reported to have attained remarkable success in the management of simple fractures and dislocations, comparable to their counterparts in orthodox medicine in Nigeria (Omoregie et al, 2015). The patrons of traditional bone-setting hinge their predilection for TBS on easy accessibility, cheaper cost, quick care, cultural belief, and pressure from family members and friends (Dada et al, 2011). Moreover, with the current socio-economic situations and the types of health needs in Nigeria, traditional bone-setting appears to be the mainstay for a segment of the population, and its abrogation appears to be impossible (Agarwal & Agarwal, 2010). The most satisfactory plan will be to find the common ground for integrative practice.

Realistically, the integration of traditional bone-setting into orthopaedic medicine practice remains the time-honoured strategy to ensure parity in healthcare choices among Nigerians (Dada, Giwa, Yinusa, Ugbeye & Gbadegesin, 2009; Nwachukwu et al, 2011; Odatuwa-Omagbemi, Enemudo, Enamine & Esezobor, 2014). In a bid to achieve this overarching goal, several measures have been advocated, notably, formal training for the TBS and their incorporation into the primary care system in Nigeria (Dada et al, 2011; Onyemaechi, Itanyi, Ossai & Ezeanolue, 2020). In addition, the West Africa Health Organisation (2019) came up with the following recommendations as the way forward to ensure a viable integration:

1. Developing a protocol for the evaluation of traditional medicines with proven quality, safety, and efficacy for the Economic Community of West African States (ECOWAS).
2. Promoting the establishment of functional Centres of Excellence on Traditional Medicine in the ECOWAS Region.
3. Entreating the region's health authorities to allocate substantial funds for the promotion of traditional medicine in the countries.

Despite the above moves, there are still glaring challenges arising from the insufficient cooperation as well as the poor coordination on the part of all the stakeholders to drive the move (Gyoh, 2010). The existing breach thus demands a pragmatic approach that embraces social integration at the community levels, taking empowerment of the community members as the hallmark of the process. However, the primary healthcare (PHC) system, which is supposedly meant to facilitate such proposal has failed to meet its mandate in Nigeria. Although the

impact of CBR may be low in Nigeria, its amenability to community-oriented activities rather than the Government's involvement with lack of political will, places it at an advantage over primary healthcare. For instance, a scoping literature review on CBR in Nigeria by Bashir, Hassan and Ibrahim, 2020 reported two studies with meaningful impacts on people with disabilities in Plateau and Akwa Ibom states. The reported studies revealed improvements in four elements of livelihood such as skill development, self-employment, wages employment, and financial services (Effiong & Ekpenyong, 2017), as well as improved independent living, vocational skills acquisition, gainful employment, improved mobility, economic reintegration in the community and orientation skills in the society (Asibi, Ukwo & Kwalzoom, 2017).

Community-Based Rehabilitation as a Conceptual Framework

The World Health Organisation (WHO) originally conceptualised CBR as a service delivery method making use of community resources to bring healthcare and rehabilitation services closer to people with disabilities (Seijas et al, 2018). Initial CBR programmes in the '80s of the last century were focussed on the provision of physiotherapy, assistive devices, and medical interventions close to where people are living. The CBR concept however evolved into a strategy with a broad focus on inclusion of people with disabilities in all spheres of life. The health perspective has been re-defined as a strategy to promote, support and implement essential or basic rehabilitation activities at the community level and, where needed, to facilitate referrals to access more specialised rehabilitation services (WHO, 2010). This evolution places a premium on CBR as an essential tool for integrating traditional bone-setting into orthodox medicine practice using primary health care as enabler of the process. Despite this opportunity, studies on CBR as a vehicle for such integration are lacking in the literature.

Many different approaches have been suggested to achieve integration of TBS into the orthodox medicine practice in Nigeria. One plausible approach is the appointment of an impartial third-party organisation that would appeal to the traditional and orthodox groups of practitioners with the view to bring the two parties together (Owumi, Taiwo & Olorunnisola, 2013). The third-party (or neutral) groups may include faith-based organisations, churches, community-based youth group movements, non-governmental organisations, women's group movements in a community, as well as advocacy groups for different health conditions. The third party must enable both parties to identify common

goals and to understand the possible roles for their distinct approaches in an integrated scheme.

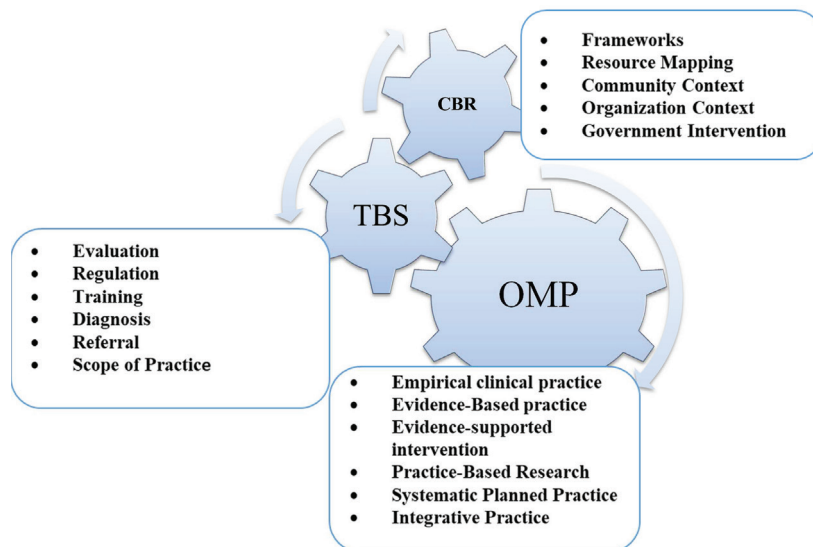
In Nigeria, most CBR projects are run by missionary organisations with support from foreign Non-Governmental Organisations (NGOs). Although there are pockets of undocumented reports in Nigeria regarding the partnership between the CBR projects and orthodox OMPs practitioners in the rehabilitation of people with various disabilities, TBS are yet to be integrated into such partnership for bone fracture management. The reason could be ascribed to the practice approach of TBS which contradicts the beliefs of the managers of CBR projects and the supporting NGOs. Many of the CBR projects are however known to partner with the TBS in the area of identification of clients in need of intervention. Given the organisational structure of the Nigerian socio-cultural set-up, including the influence of the high-class individuals, the CBR model may be well-suited for the purported third-party role, with emphasis on linkage, collaboration, training, referrals and research as the focal points.

Linkage

Community-based rehabilitation typically forms a central connecting point for the community, OMPs and TBS, as illustrated in Figure 1.

Fig. 1: Conceptual Framework for Integrating TBS and OMPs

Personal interaction of the authors with TBS in Tiv Land (North-Central Nigeria)



shows some level of willingness on the part of the bonesetters to cooperate with the orthodox systems. However, the missing link has always been the rightful platform to facilitate the collaboration in such a way that professional identity of both parties are maintained and safeguarded. In this regard, the dignity of the TBS (in particular) during the process will not be at stake. Community-based rehabilitation programmes could exert a positive influence on the attitude and beliefs of the community members for the benefit of the clients owing to the impending integrative knowledge and way of thinking. Using a CBR model, the complex therapeutic procedures could be demystified and simplified to the understanding and acceptance of the common man at the community level. The exemplary role of Christoffel Blinden Mission (CBM) in Nigeria is a case in point. Based on the authors' experience as key players in the community project under the aegis of CBM-sponsored CBR programmes in some states of Nigeria, the success recorded in integrating orthodox physiotherapy principles into the community is a clear signal of the feasibility of the CBR model for integrating traditional bone-setting and orthodox medical practice. The exemplary role entails mapping local resources and engaging communities, churches, mosques, and local health facilities to identify people with disabilities, including those with post-fracture complications. The identified people could either be managed locally or referred to a specially assembled team of professionals for appropriate management. Although the role has largely been one-sided in favour of OPMs, it can be expanded to TBS to utilise the services of both parties and ensure referral where such is found appropriate.

Collaboration

The TBS offer direct contact care at community level, which places them at an advantage as major stakeholders in CBR. According to Omololu, Ogunlade and Gopaldsani (2008) and Omoregie et al. (2015), about 85% of people with fractures in Nigeria consult TBS first. Indeed, traditional bone-setting has been found to show remarkable success in the management of close and simple fractures as well as joint dislocations (Omoriegie et al, 2015). It thus follows that the indigenous knowledge inherent in the TBS can be enhanced to enable them to identify the scope of their practice and make necessary referrals to OMPs to ensure safe and quality care of people with fractures. In that case, the TBS would be seen to practice in a discrete pattern that aligns with acceptable standards. On the other hand, the OMPs could be educated on the potential role of the TBS at the grass roots, based on their popularity, and be well-abreast of their practices. If

adequately trained in the basics of orthopaedic care, TBS may provide essential and culturally relevant health services to their communities. They can serve as the first point of contact at the primary healthcare level, thereby reducing the burden on secondary and tertiary health institutions (Owumi et al, 2013). For instance, Kwame (2021) found a positive attitude towards integration of orthodox and traditional medicine among traditional healers, healthcare service consumers and orthodox healthcare practitioners in the Northern Region of Ghana. The author advocated an integrative model to allow the use of medical innovations in traditional medical practice (e.g., X-ray), support client co-referrals, ensure collaborative efforts towards ensuring clients' wellness, establish a traditional medicine unit at the out-patient departments for healthcare choice, adjust curriculum to incorporate the rudimentary knowledge of traditional medicine while also creating space for cross-information and information sharing among the stakeholders.

One of the avoidable downsides of traditional bone-setting is the lack of accessibility to assistive devices. Through CBR programmes, local resources (human and materials) can be harnessed to provide cost-efficient and cost-effective devices similar to the custom-made brand. Such devices include crutches, wheelchairs, ankle-foot orthotics, toe-raise and slings that can be made by engaging community vocational operators including cobblers, carpenters, welders and tailors. In this case, the stakeholders in CBR can be encouraged to utilise the services of TBS, provided that the service is within their scope and they are trusted to produce quality care in light of the needs and convenience regarding the accessibility of the services and evidenced-based approach (Nganwa, Batesaki & Mallya, 2013).

Training

Several authors have suggested training provision for the TBS, in particular for training and standardisation of the skills (Dada et al, 2011; Onyemaechi et al, 2020). While this suggestion is plausible, it must imbibe the principle of integration. It is the candid view of the authors of the current review that such training must not be anchored by the OMPs. It is probable that the anxiety to safeguard professionalism would not encourage orthopaedic professionals to share more skills and resources with the TBS due to a lack of trust and confidence in the competence of the TBS. Interestingly, the TBS are also aware of the level of mistrust among OMPs towards them. This scenario can be alleviated by implementing CBR programmes through which trainings are organised at the community level

for all the stakeholders in the project, i.e., TBS, clients, family, and community members. Also, there is a training need for the OMPs on attitudinal and behavioural change towards the process, to be able to engender compliance and acceptance of TBS and their operation within the communities. To ensure mutual respect among the stakeholders, the facilitation of workshops and interventions at the hospital and community levels, in this regard, should be anchored by the key players in CBR projects such as Non-Government Organisations. This move will not only preserve the values of the TBS but also create positive sensitivity towards genuine collaborations among the stakeholders.

Referrals

One of the seemingly identified challenges with traditional bone-setting practice is the absence of referral by the practitioners (Dada et al, 2011). The lack of a referral mechanism between the two groups is occasioned by the lack of integration. Through the proposed concept of the CBR programme, the TBS will be sure of their limits and ensure timely referrals to the OMPs to forestall avoidable post-fracture complications. More often, complicated fracture cases are not referred to the hospital which often potentiates gangrenous extremities and eventual amputation in the long run. Some of the problems militating against referral can be linked to both clients' and providers' determinants. The former could range from high cost of hospital services, perceived long protocol, and ardent belief in the attached values, while the latter's determinants may include unwillingness to refer, lack of confidence and belief, and personal core values. Referral can be facilitated in CBR projects from community centres and outreaches to big hospitals in many ways, including provision of transport and looking for donors to defray hospital fees. Undoubtedly, introducing the CBR programme to mediate the integration of TBS and OMPs will drive the referral system.

Research and Output Disseminations

Most studies on TBS are hospital-based and would not yield answers to many pertinent issues. In Nigeria, with the highest number of with highest number of people with living disabilities in Africa, only two impact studies on CBR were identified in a scoping literature review (Bashir et al, 2020). Community-based rehabilitation is not excessively concerned with constricted clinical rehabilitation questions, but with wider issues involving models of service delivery, community participation, empowerment, and improvement of social conditions of persons

with disabilities (Udoh, Gona & Maholo, 2013). Key players in CBR may need to explore the community further, through research, to understand the social and cultural background of bone-setting practice in various communities in order to give direction to policy formulations concerning integrative model of healthcare delivery. The CBR-oriented research should involve the generation of pragmatic information through qualitative research. The output of such exploration should be made available to those who need it, via the right platforms.

CONCLUSION

Traditional bonesetters are strategically placed in the community, thereby making them potential sources of succour to individuals in need of fracture management. Given the high patronage of TBS, its integration with the OMPs in the management of fractures would provide the desired health outcome. Community-based rehabilitation model is seen as a useful tool for integrating TBS and OMPs due to its wide context to promote best practices, considering the combined advantages of western knowledge and acceptable cultural practices. Incorporating the CBR concept to drive the integration will engender self-appraisal among the stakeholders to appreciate their roles, with the view to refine and promote good practice. This review has great implications for better management of fractures and the attendant complications in Nigeria, especially considering the high patronage of TBS. Integration of TBS and OMPs through the CBR model may facilitate better access to safer healthcare for fracture management of community dwellers. Adoption of the CBR model could put an end to the long-standing bewilderment that continues to trail the integration process and serve as a vehicle for integrative healthcare in Nigeria.

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NLR - until No Leprosy Remains is a Dutch non-profit organization committed to a world without leprosy and its consequences. It tries to achieve this by supporting health authorities in countries where leprosy is prevalent. NLR promotes the independent social and economic functioning of leprosy patients and their families. By supporting scientific research NLR wants to improve the effectiveness of leprosy control.

NLR is a member of the International Federation of Anti Leprosy Associations (ILEP). NLR supports national health authorities in over twenty countries with endemic leprosy problems, collaborates with international partners in leprosy control, and works professionally and efficiently.

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The Liliane Foundation contributes to a world that is open to everyone and in which poor children with disabilities can develop and use their talents. The foundation collaborates with local partners in Africa, Asia and Latin America to raise awareness of the 'exclusion' of these children and to remove the barriers that they suffer because their environment is not set up to allow their participation.

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