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Editorial

HELP: Help Educate Low-income countries to set their own Priorities

Thanks to all authors and reviewers, we once again have a very interesting issue of this journal. The few letters to the editor that have been submitted and an interesting guest editorial show that this may slowly develop into a journal that is increasingly going to play a role in global and local debates about disability, development, and the detested and confusing term and approach for some: rehabilitation. However, the response to my appeal in the latest issue to involve you, as readers, in the debate about the future of the journal has, unfortunately, been marginal. I truly hope that you as readers, authors, and reviewers, are able to take time to respond to the content of articles published as well as to editorials in which some of us are trying to help others to reflect, to trigger discussion, and to influence the debate about developments in the field of disability, development and rehabilitation. In my own editorials, I will continue to mirror theories and strategies to the reality of what I and others observe and experience in the field. What is put down on paper in the form of legislation and policies, and also what is stated at conferences, is often extremely different from what one sees in the field.

I, however, assume that there is consensus about the status of rehabilitation in low-and middle-income countries at peripheral rural level - at community and primary healthcare level institutions, rehabilitation is almost unavailable to most people. Even district hospitals clearly lack capacity for outpatient rehabilitation. I am not arguing here that rehabilitation is a condition for being included in society. That would be by far too simplistic. However, one would be rather ignorant if rehabilitation is not seen as important.

Those who turned their backs on CBR hopefully realise that community mobilisation and advocating for disability rights, albeit both essential, have so far not been able to make a distinct difference in the lives of people. Isn't it time to start with a package I call HELP: Help Educate Low-income countries to set their own Priorities? Let's be honest: there is a serious scarcity of resources in low-income countries. One can make grand plans to meet the needs of people living in low-income countries, embark on the introduction of training professionals at universities, copy western models and standards, but… can and will such countries be helped by this? Can they afford highly trained professionals who will

most likely end up working in the private sector? Are we not too greatly focussed on applying western solutions to non-western situations and is this in fact not a reflection of the arrogance of professionals thinking only within the confines of their own profession, unwilling to give up their power? Maybe that is too harsh, and I apologise to all who work relentlessly towards a better world but… the McDonaldisation of public health efforts which David Werner was criticising in the 1980s, can these days be clearly observed, namely, global development, uniformity, protocolisation. It can be worse however, whereby countries and local organisations (almost) feel obliged to accept whatever western experts and expert organisations prescribe. If they don't accept their ideas, it may even have repercussions in the form of withdrawing funding. Can it be that neo-colonialism is going that far? Frank Bron in his guest editorial is milder in his opinion but also very clearly shows that non-western situations ask for local solutions. Where someone (not necessarily western, by the way) may feel that it is undignified to transport a person with a disability in a wheelbarrow, it may very well be the best and most appropriate way of doing so in an extension of the Kalahari desert. One may have the best and most modern technology at one's disposal but those working in the field know that the hills of Rwanda or Cameroon are like mountains for people with mobility problems. No accessibility guide will help them to change that situation!

A few years ago, the director of a development agency was visiting a low-income country in Asia. The day that we met– by accident – in a small guesthouse, she told me about her meeting with the Minister of Health that same day. She had hoped to convince him to invest more in the field of rehabilitation, but in vain. Upon her remarking that 15% of the country's population was with a disability, he told her without much diplomacy that while she thought this to be true, local studies showed a prevalence rate of less than 4%, which was the rate with which his department was working. He stated that his country was facing many other and more pressing priorities, including life-threatening diseases and natural disasters. Mention of the 15% prevalence rate didn't make much of an impression, as the Minister knew that many of them were well able to cope with their lives, and many of them belonged to a group of old people who accept that their functions had started deteriorating. It would perhaps have made more of an impact if the director had started to talk about the prevalence of people with disabilities who would need certain rehabilitation services!

I realise that it is easy to criticise. However, it is also very easy to accept policies and strategies from global organisations, donor organisations and experts, without critical appraisal. At the same time, there is an increasing consciousness among people on the African continent for instance, that it is time to view the world, and certainly their world, not only from a western middle-class male dominated perspective but also from indigenous perspectives. The recently published book *Disability in Africa*[1] is ground-breaking and acknowledges the demands and challenges of particular African contexts. I have just bought the book and am tempted to leave my daily work and read it, as the titles of the various chapters fill me with enthusiasm. It is a pity that the book is so expensive, however, for it seems an indispensable source of information for those working in the field of disability and development in Africa. For instance, the book talks about the way in which culture and religion shape ideas about disability and its consequences for policymaking in the field of health, education, (community) rehabilitation and development.

Recently, a colleague and I had the privilege of conducting training for a large group of people in Burundi. Half of them had a disability. Amazingly, and although the group represented a large variety of disabilities (blind, deaf, having albinism, with physical disability in various forms and degrees), there was a tendency to always talk about 'the disabled' who are discriminated, 'the disabled' who have no access to basic resources, 'the disabled' who are affected by climate change. It took quite a while before we were able to make people realise that 'the disabled' do not exist. It is a very diverse group in terms of gender, age, socioeconomic status, and in terms of the type and the severity of the disability. For someone with albinism the effects of climate change are very serious, while for others it may be marginal. Certain groups may be more stigmatised than others. The list goes on…It was only then that we discovered that this could be the result of years of working with western donor organisations whereby people time and again hear the same global messages, get the same global information, celebrate international disability day and almost forget the richness of their own (cultural) knowledge. They forget that, for instance, traditional leaders and religious leaders have authority and that if one wants to be more successful in lobby and advocacy, one should start with recognising their way of thinking, their ideas about disability, their mindsets, the local governing systems and structures. It was then also that we realised that our way of looking at lobby and

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1   Toyin Faloloa and Nic Hamel (eds), Disability in Africa: inclusion, care and the ethics of humanity, University of Rochester Press, 2021.

advocacy was broader and more comprehensive than theirs, but that their way of viewing and doing lobby and advocacy is embedded in local political systems with all corresponding restrictions attached to it.

In front of you lies the new issue of the DCID journal. In the last editorial, I referred to the new vision paper for the journal. While development – maybe by definition – is usually slow, I can inform you that currently very promising discussions are taking place with an African university to ensure that the journal will be embedded within an organisational structure that is best equipped to publish it. I am delighted with this development for many reasons. I hope to inform you in more detail about this development in the coming year.

Finally, I would like to refer to an excellent scoping review by Gwarega Chibaya et al on the Implementation of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in Africa (see this issue of the journal). Without going into detail, I can tell you that on reading the review one realises there is still a lot of work to be done to ensure that persons with disabilities will benefit from the promises made by governments that signed and ratified the UNCRPD.

Wishing you a peaceful and joyful 2022!

Huib Cornielje

Guest Editorial

(Neo) Colonialist Attitudes in International Cooperation: Imposed, self-imposed or an easy excuse? Plus some suggestions to overcome them

Frank Bron*[1]

Guest Editor

For most of us, much of what we do is done in a certain way simply because we are used to doing it in that particular way. Whether from Austria or Australia, from China or Chile, we usually do not question how we do things because most people around us act the same way. That is all right until we meet someone who does things differently. This can be interesting or hilarious, except when we are convinced our way is better - or should be the standard. And even when both parties are convinced the other is wrong, there is not necessarily a problem – they can simply walk away and ignore each other. Problems arise when both parties have to work together and there is a power difference between them. A real or a perceived power difference.

Reinforced Concrete

Jessica is a Guatemalan architect living and working in the Netherlands. When she wanted to redo her house, she was shocked to find the walls did not include one reinforced concrete pillar every three meters or so, as that to her was how you build a decent house – in Guatemala. While it is not illegal to use reinforced concrete pillars in the Netherlands, it is much more expensive than to build brick walls with regular concrete pillars at the corners, at best. Soon Jessica realised that, as there are virtually no earthquakes in the Netherlands, it was not necessary to build an earthquake-proof house. But to her, as a Guatemala-trained architect, it did not feel right.

It also felt awkward for her to include large windows in her design. First of all, glass walls are almost impossible to construct in Guatemala because of the aforementioned reinforced concrete pillars, and students of architecture are not

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*   Corresponding author: Frank Bron, Email: frankmar@versatel.nl

really taught how to construct them. While Guatemalans prefer to keep the hot tropical sun out, in the Dutch temperate climate sunlight is usually welcomed inside the home. Eventually Jessica appreciated the fact that architecture specific to the local circumstances was required. Currently she is very happy in her fully refurbished house.

Attitudes

Not only do we tend to do as we always did, our attitudes, norms and values are also shaped by our own societies and upbringing. A former colleague of mine, on one of his first visits to Africa, saw a man with a disability being transported by wheelbarrow. My colleague (let's call him Peter) felt this was degrading for a person with a disability (Ahmad – not his real name) as well as uncomfortable for Kofi, the friend transporting him. Fortunately, having been sent there as an expert in a development project focusing on people with disabilities, Peter was in a position to purchase a wheelchair to improve the situation. The shiny new wheelchair, a sign of modernity and a step forward towards independence for Ahmad, made everybody happy - initially.

Soon however, they all realised the wheelchair was actually a step back. The streets in the village were uneven, the sidewalks were high and hard to access, and in the rainy season the wheelchair's four wheels often got stuck in the mud. When that happened, Ahmad needed more than just one friend to free his wheelchair and push him to his destination.

While this is an interesting instance about the introduction of inappropriate technology, is it also an example of a neocolonialist attitude? And if so, by whom? The foreign expert was trying to help and did it in the way he knew: spend some money and purchase a wheelchair. Ahmad was happy to be helped by the foreign expert and looked forward to going places on his own. Kofi might have had some reservations about the practicalities of using a wheelchair for his friend to get by in his village but hey, the foreign expert not only suggested it (and after all he was the expert) but also paid for it.

Eventually realisation dawned that the problem was not the use of the wheelbarrow but rather the local infrastructure. If the infrastructure was improved, not only Ahmad but the entire community would benefit. The improvements would help in the fast and smooth transportation of goods, enable pedestrians and people with disabilities to move about, children could play outdoors safely, pregnant

women and the elderly could perhaps do with some benches, and cyclists or street vendors would be able to go about their business without being run over by buses.

Colonialism

Was the solution implemented by the European expert an example of (neo) colonial thinking ("I know best")? Or, alternatively, was the acceptance of the solution by the two Africans mentioned in this true story, an example of colonial thinking ("He's from Europe, he knows best")? In order to answer those questions, let us first talk about the meaning of 'colonialism'. Based on a common definition, we could say colonialism 'is control by one power over a dependent area or people. It occurs when one nation subjugates another territory using military means with the aim of exploiting that territory's resources (including people). In the process the colonial power usually forces its own language and cultural values upon the local people while actively oppressing the colony's own interests.'

When speaking of colonialism, usually the European conquest of large parts of the overseas world comes to mind. However, the story is more complicated than that. The Russian conquest of Siberia (not overseas), the Japanese conquest of Korea (no European power involved) or the Aztec conquest of their neighbours in pre-colonial Mexico, to name a few, can all be called colonisation. Colonisation was often justified by religious and economic arguments. Having said that, there were different ways in which colonies were founded and managed, but they were all run with the best interests of the colonial power in mind.

Neocolonialism

In the end, many of the colonial rulers as well as many of those oppressed by them came to accept the superiority of one group (the colonialists) and the inferiority of the other group (the colonised). When the latter eventually kicked out the former, both groups had to come to terms with the idea of 'equality'. Neocolonialism then refers to a situation where the former colonial power still tries to control the resources or politics of its former colony through non-military means, usually through economic or financial pressure on the authorities of the former colony.

It cannot be denied that, by and large, the citizens of erstwhile colonial powers are wealthier than those living in the former colonies. Many former colonial powers are still more politically stable and have better education and healthcare systems.

Yet the relationship initially forged through violence is still there. The ties between India and England, Senegal and France or Suriname and the Netherlands remain strong and diverse, ranging from speaking the same language, having the same religion, sharing cultural phenomena and, indeed, sharing a common history. But that does not necessarily mean, and here we come to the central message of this article, that one side still knows best or that both sides truly understand each other simply because they speak the same language.

For many involved in international cooperation for development, the donor's norms are still the standard and the exchange between partners is usually one-way traffic. Remember Peter, Ahmad and Kofi? Just as Peter did not take the local circumstances into consideration when he applied his own solution to Ahmad's problem, sometimes World Bank solutions do not work in countries where the local government is weak or absent. In other words, Ahmad wanted a fancy wheelchair and was not in a position to question Peter's solution. Kofi, Ahmad's friend, was hoping he could spend less time pushing Ahmad around so he did not challenge Peter either. In the end, Peter stayed around long enough to see his solution did not work and never looked down on wheelbarrows anymore.

It does not mean that any of the three people in this example acted 'neocolonial'. The activity was truly intended to benefit Ahmad – as well as Kofi and Peter (a good result to show for). If only Kofi had explained to Peter about the muddy streets in the rainy season, then the latter would have appreciated the (to him) uncommon use of the wheelbarrow more. This reminds me of a moment of personal 'intercultural' growth. While in Japan, my friend Tomoyoshi offered me a cup of green tea and. As I preferred black tea, I asked, "*Don't you have normal tea?*" To which Tomoyoshi correctly replied, "*This **is** normal tea*".

Six Goats in the Field

In other words, even **if** the foreign expert knows best, it is the local counterpart who has to implement the solution. The representative of the donor organisation may be a theoretical expert in a specific area (transportation, therapy, animal husbandry, etc.), but the local expert should be able to foresee whether a proposed solution is feasible or not. Usually the foreign expert is only 'in the field' for a relatively short period and consequently cannot know all the ins and outs of the local situation. Furthermore, he or she is usually under a lot of pressure to identify problems, come up with solutions and show quick results. But that does not mean the foreign expert, evaluator or controller knows it all – they just need

to receive correct and complete information, and that is where local expertise comes in.

Usually foreign experts are open to additional information about their field of interest, especially if that could improve their work. What they need are assertive, well-informed local counterparts as resource persons. The word 'counterpart' itself already implies a horizontal relationship, but in real life counterparts are often seen as mere contact persons. It is not that foreign experts intend to bypass local experts; it is just that they are under pressure (financial and otherwise) and so, all too often, they propose the same trick that worked elsewhere or that he/she feels is right - remember Guatemalan Jessica and her Dutch house?

Furthermore, local experts are not, by the colour of their passport, better informed or more open to input from the field. Frequently they are men from wealthy families and have no personal experience with poverty alleviation among women or community development. When I took an online course 'De-colonising evaluation' at a university in South Africa, one of the staff members commented, *"Local evaluators are often much more arrogant and more difficult to work with than European evaluators."* In other words, nationalising evaluations of international development activities is not the same as de-colonising these evaluations. A colonial attitude does not depend on one's nationality.

Arrogant or accessible, a foreign PhD or not, millions of dollars in the bank versus six goats in the field, in the end it is the local population that has to deal with the consequences of foreign interference. The days of thinking that outsiders know best are long gone. And while it is not true either that a local farmer always knows more than a United Nations expert, they should at least try to team up so that both sides can reap long-term benefits from foreign technological or financial interventions. Indeed, to many people in donor organisations, implementing organisations, recipient organisations and others, true collaboration at eye-level may still be uncommon. However, 'equality' and 'partnership' have officially been two of the cornerstones of international cooperation. So while there is no need to quarrel with their donor, recipients not only have the right but also have the professional obligation to stand up for their own ideas and solutions, in short: to be assertive. After all, it is their future that is at stake.

Assertiveness

While working for a donor organisation, I once visited Colombia. My local counterpart, Daniel, had to overcome a series of issues and expected me to come

up with the solutions. He was a true expert in areas like CBR and rehabilitation, while I was relatively new to these fields. I urged him to come up with solutions and proposals but he was very reluctant to do so. Especially, we both knew, since he was used to my organisation (and his superiors) telling him exactly what to do. So I wrote the word 'ASSERTIVENESS' in capital letters on a piece of paper, suggested he should stick it on the wall over his bed so he would see it first thing in the morning, and said that I needed him to come up with solutions. True, in the end it was up to me to decide on funding his proposals so Daniel depended on my decision. At the same time, for my work to be successful, I depended on Daniel's knowledge of local circumstances and his professionalism.

That evening we could have accused each other of a neocolonialist attitude (the 'dependent local counterpart' versus the 'know it all donor representative') but we did not. In the end we both realised we had to team up for the benefit of children and youth with disabilities, so we said goodnight and went to sleep. The next day it turned out Daniel had taken the message to heart. He took the lead in discussions at his office, came up with strong proposals and later it turned out that many of his local solutions to local problems actually worked! This was not only good news for Daniel's organisation and local beneficiaries, but also for my organisation and its financial supporters who got value for their money.

In other words, (neo) colonial attitudes are a factor in international cooperation but oftentimes good communication and professional, horizontal cooperation can overcome such attitudes.

ORIGINAL RESEARCH

International Continuing Education for Rehabilitation Workers in Honduras: a Pre-test, Post-test Evaluation

Adriana Angarita-Fonseca[1, 2], Stacey Lovo[3*], Isabel Cristina Gomez-Diaz[2,4], Julia Bidonde[5], Martha Liliana Hijuelos-Cardenas[2], Maria Basualdo[6], Kalyani Premkumar[7], Melvin Urbina-Nuñez[8], Angela Busch[3]

1. Universite du Quebec en Abitibi-Temiscamingue & Centre de recherché de Universite de Montreal,Canada
2. Universidad de Santander, Colombia
3. School of Rehabilitation Science, University of Saskatchewan, Canada
4. Neurotrauma Center IPS, Bucaramanga, Colombia
5. York Health Economic Consortium, UK , & Norwegian Institute of Public Health , Norway
6. Ontario Public Interest Research Group, Canada
7. College of Medicine, University of Saskatchewan, Canada
8. Centro de Rehabilitacion Integral del Litoral Atlantico, La Ceiba, Atlantida, Honduras

ABSTRACT

Background: The knowledge of Honduran healthcare workers who deliver rehabilitation services can be enhanced by support from community-engaged academic collaborations outside the country.

Objective: This study aimed to evaluate reactions and learning linked to two continuing education workshops for rehabilitation workers in northern Honduras.

Method: A pre-test post-test study design was used. In September 2017, faculty from Canada and Colombia, together with health professionals from Honduras, facilitated two neurorehabilitation workshops - one in a rehabilitation centre and the other in a family support organisation located in northern Honduras. The participants were physiotherapists, physicians, nurses and educational professionals, as well as a psychologist, kinesiologist, and non-professionals trained onsite. Seventeen participants attended the 'Acquired brain injury/spinal cord injury workshop' (adult workshop), and 15 attended the 'Rehabilitation for children with impaired neuromotor development workshop' (paediatric workshop). They completed three questionnaires before the workshops: one on sociodemographic information; one related to knowledge; and, the Modified Stages

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*   **Corresponding Author:** Stacey Lovo, Assistant Professor, School of Rehabilitation Science, University of Saskatchewan, Canada. Email: stacey.lovo@usask.ca

of Learning Questionnaires (MSLQs). Three questionnaires were completed after the workshops: the Modified Kirkpatrick; a knowledge questionnaire; and, the MSLQ.

Results*: Most of the participants agreed that the workshops had positive effects in two of the four Kirkpatrick levels that were evaluated: reaction and learning. In the MSLQs of the paediatric workshop, there was a statistically significant change in the percentage of participants who moved from scanning/evaluation stages in the pre-test to learning/gaining experience in the post-test, in three of the six topics. Three of the knowledge questions showed important learning effects.*

Conclusion and Implications*: Workshops offered through an international collaboration resulted in enhancing learning and knowledge of neurological rehabilitation workers in Honduras. This initiative has the potential to improve the quality of care for people with neurological conditions in the region. Participants evaluated the workshops as relevant and held very positive attitudes about the perceived outcomes. The inclusion of local practitioners in planning the workshops and selecting the topics appeared to have aided their relevance. It is recommended that workshop planners take adequate time to ensure relevancy.*

Key words: *physical therapy specialty, rehabilitation, nervous system diseases, continuing education, global health*

INTRODUCTION

Honduras, situated in Central America, is a country of nine million people. It hosts a mix of traditional culture and modern lifestyles (Central Intelligency Agency, 2019). Based on 2013/2014 statistics, an estimated 4.6% of the Honduran population aged 18-65 had a disability, i.e., 220,800 out of nearly five million people (Flores et al, 2015). Colon, Atlantida and Yoro, the geographical area of study, had a disability prevalence of 4.3%, 5.5% and 6.1%, respectively (Flores et al, 2015). In addition, extremely disabling sequelae of non-fatal injuries have been documented, such as organ removal, loss of limb and paraplegia (Yacoub, Arellano & Padgett-Moncada, 2006).

Health System in Honduras

Bermudez-Madriz, Saenz, Muiser & Acosta (2011) described the Honduran health system as two-tiered, with public and private providers. As part of the

public system, the Secretary of State for Health (Secretaria de Salud) provides direction for the health system as a whole and also provides health services to the population. The Secretary of State for Health serves the whole population but mainly takes care of those who are unemployed and live in poverty in urban and rural areas. The private sector provides health services to 5% of the population, namely those with enough income to pay for health services. It is estimated that 17% of the total population has no access to any health service at all (Bermudez-Madriz et al, 2011).

In Honduras, there are several rehabilitation clinics for people with disabilities (United Nations, 2015). The Secretary of State for Health operates five clinics located in public hospitals, and two hospitals for persons with mental or psychosocial impairments (United Nations, 2015). Furthermore, the Honduran Social Security Department (a government body that provides pensions and healthcare coverage) has two rehabilitation centres in the main cities of San Pedro Sula and Tegucigalpa that employ physiatrists and qualified technical staff and have modern rehabilitation systems (United Nations, 2015). In addition, the Teleton Foundation (a non-governmental organisation) operates six rehabilitation clinics, none of which are located in northern Honduras (Teleton Foundation, 2018). In La Ceiba, Atlántida, the Centro de Rehabilitación Integral del Litoral Atlántico (CRILA) employs physiatrist and qualified technical personnel such as functional therapy technicians, and in Tocoa, Colon, the Centro de Rehabilitación Integral del Litoral Atlántico (CRICOL) operates with functional therapy clinicians. Honduras has adopted community-based rehabilitation guidelines, as advocated by the World Health Organisation and the Pan American Health Organisation, as a strategy to improve access to rehabilitation and community integration for persons with disabilities (United Nations, 2015). Community-based rehabilitation is a rehabilitation approach used in rural areas. However, there are many barriers to the implementation of community-based rehabilitation in rural communities due to limited local professional capacity and administrative and language barriers (United Nations, 2015). Similar to other low- and middle-income countries, rehabilitation centres and services have sprung up in a haphazard manner and are fully reliant on philanthropic funding sources provided by Honduran citizens and non-governmental organisations (Kay, Kilonzo & Harris, 1994; Descoteaux et al, 2018).

Rehabilitation Training

Despite the number of people with disabilities in Honduras, there is only one private university that provides a four-and-a-half-year Baccalaureate programme in rehabilitation (a combined physical therapy and occupational therapy degree) but as yet has no graduates. Other rehabilitation training programmes available in the Universidad Nacional Autonoma de Honduras include a medical degree in physical medicine and rehabilitation, a technical degree in functional therapy, a Baccalaureate degree in phono-audiology, and a diploma in integrated community rehabilitation. There is no formal system of post-professional training opportunities to support rehabilitation workers such as physical, occupational or speech language therapists, nor training beyond the Baccalaureate level.

According to the 2013 census (Instituto Nacional de Estadistica Honduras, 2013), in Colon, a northern province of 271,723 people, there were no qualified rehabilitation workers: physiotherapists, phono-audiologists, functional/physical therapy technicians, or community rehabilitators (Figure 1, Map A). Moreover, the distribution of self-identified rehabilitation workers in Colon was 0.4 per 100,000 people (Figure 1, Map B). It is likely that the higher density of self-identified rehabilitation workers indicates that other professionals and community members such as nurses, primary school teachers, special education teachers or family members have attempted to fill the gap in the rehabilitation workforce in the province.

As the country is now building capacity in rehabilitation, regulatory structures and/or professional associations for the professions of physical therapy, occupational therapy or phono-audiology may emerge. The slow development of the rehabilitation professions and small public investments in rehabilitation infrastructure greatly restrict the care and treatment available for the population.

Figure 1: Distribution of Trained Rehabilitation Workers (Map A) and Self-identified Rehabilitation Occupation Index (Map B) by Province in Honduras
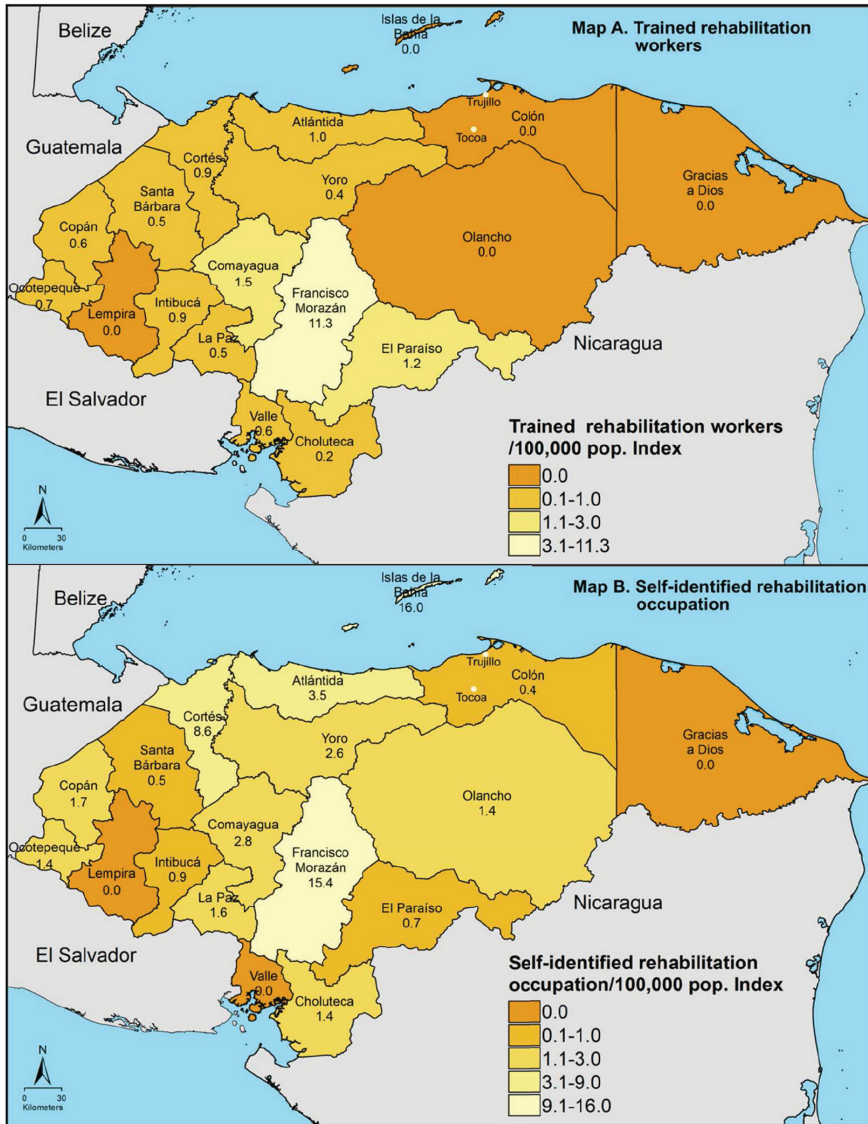
Source: Prepared by the first author, based on data from the Instituto Nacional de Estadistica Honduras (2013)

Since 2016, a grassroots organisation initiated by the authors of the Network of Rehabilitation Workers of the Americas (Red de Rehabilitadores de las Américas) has undertaken to support the professional education needs of the rehabilitation workforce in the northern states of Colon, Atlantida, and Yoro by developing north-south collaboration and sponsoring a visiting professor programme.

The Network of Rehabilitation Workers of the Americas includes members from the University of Saskatchewan in Canada, Universidad de Santander in Colombia, from Norway, and rehabilitation workers in Colon and Atlantida in Honduras. Workshop curricula, developed by rehabilitation professors from the aforementioned universities and the staff of local organisations, have been implemented as part of this programme. The objective of this study was to evaluate reaction and learning – two of the four levels as described in the Kirkpatrick Model - linked to two continuing education workshops for rehabilitation health workers in these states, designed by an international group of academics and community-engaged rehabilitation workers.

Theoretical Models

Evaluation of participants' neurorehabilitation knowledge and learning was based on the Kirkpatrick Model (Kirkpatrick Partners LLC, 2009; Praslova, 2010) and Slotnick's four Stages of Learning Model (Slotnick, 1999; Moore & Slotnick, 2006). The Kirkpatrick framework was originally designed to evaluate human resource development training programmes (Praslova, 2010; Kirkpatrick & Kirkpatrick, 2016). It specifies four levels of training evaluation: reaction (engagement, relevance, and learner satisfaction); learning (acquisition of intended knowledge, skills, attitude, confidence, and commitment); behaviour (critical behaviours, required drivers, on- the-job monitoring); and results (the degree to which participants apply what they learned during training).

The Modified Stages of Learning Questionnaires (MSLQs) use clinical scenarios constructed to address learning objectives (Slotnick, 1999). According to Moore and Slotnick (2006), the learner's level of engagement with respect to a given learning objective can be classified into one of four stages of learning: 1) Scanning – the learner is aware of potential problems that might require attention; 2) Evaluation – the learner evaluates the potential problems on the basis of applicability to his/her own situation, the likelihood of finding a solution, whether there are resources available for learning to develop solutions to the problems, and whether the learner is learning how to solve the problem relevant for practice; 3) Learning – the learner gains skills and knowledge applicable to the problem; and, 4) Gaining experience – the learner puts what has been learned into action.

The Network of Rehabilitation Workers of the Americas hypothesised that a better understanding of the effects of the workshops can give insights to improve future efforts to build rehabilitation capacity in Honduras.

Objective

The objective of this study was to evaluate reaction and learning linked to two workshops that were delivered through the visiting professor programme for health rehabilitation workers, in two rural cities, Tocoa and Trujillo, in northern Honduras.

METHOD

Study Design

A pre-test post-test design was used to evaluate the reaction and learning effects of two workshops. Based on initial feedback, the questionnaires were modified and translated between English and Spanish by bilingual members of the team and approved by the Continuing Education in Rehabilitation Science unit at the University of Saskatchewan. The language of the workshops and data collection was Spanish. The sociodemographic questionnaire, the MSLQs and Knowledge Questionnaires were administered to the participants online or in paper format prior to the workshop (Figure 2). The MSLQs were administered immediately after the workshop as post-tests. The MSLQs and Knowledge Questionnaires were sent to participants one month after the workshops, in paper form.

Figure 2: Flow of the Study (MSLQ = Modified Stage of Learning Questionnaire)
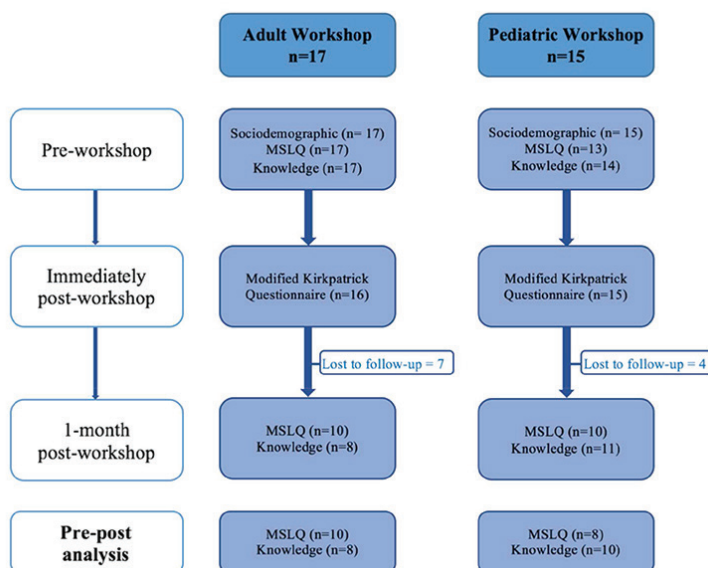
Participants

The workshop on adult acquired brain injury/spinal cord injury (hereafter referred to as adult workshop) was held in Tocoa, Colon. Individuals working in healthcare, with an interest in neurological rehabilitation, were invited by the host rehabilitation centre, CRICOL, through email sent to other rehabilitation centres and hospitals in the region. Seventeen participants attended this first workshop. The second workshop, focusing on the rehabilitation of children with impaired neuromotor development (hereafter referred to as the paediatric workshop) was held in Trujillo, Colon, and was attended by 15 individuals. All rehabilitation workers from the host centre - Little Hands, Big Hearts - a family support organisation, and those working at CRICOL were invited. Five participants attended both workshops.

Workshops

The third author, a Colombian physiotherapist with a Master's degree in neurorehabilitation who has been teaching at the Universidad de Santander, Colombia, for more than 10 years, conducted the adult (neurorehabilitation) workshop with the assistance of a physiatrist and a local physiotherapist. The physiatrist had 2 years' experience in neurorehabilitation in public and private Honduran clinics, and the local physiotherapist 7 years. The third author instructed the paediatric neurorehabilitation workshop independently.

Workshops were planned in partnership with four institutions: 1) CRICOL in Tocoa and Little Hands, Big Hearts in Trujillo, 2) the School of Rehabilitation Science, University of Saskatchewan, Canada, 3) Universidad de Santander, Colombia, and 4) Continuing Education in Rehabilitation Science, University of Saskatchewan, Canada. The themes were selected considering the reported needs of the local rehabilitation workers from CRICOL in Tocoa and Little Hands, Big Hearts in Trujillo. After several online meetings between the members of the Network of Rehabilitation Workers of the Americas and local rehabilitation workers, the learning objectives for the workshops and clinical cases were developed. In addition to considering the local context, the workshops were carefully constructed with evidence-based learning objectives using Bloom's taxonomy (Bloom, Krathwohl & Anderson, 2001).

The adult workshop included nine objectives related to neurorehabilitation in adults with acquired brain injury, spinal cord injury, and cerebral vascular accidents (Appendix 1) and was conducted over two consecutive days (12 hours

duration). It had lectures using PowerPoint, interactive content (class discussion), demonstrations, practical activities among peers, and case discussion and assessment/treatment demonstrations on an adult client with cerebral vascular accident.

The paediatric workshop addressed seven objectives linked to rehabilitation for children with impaired neuromotor development (Appendix 2). It was a one-day workshop (7 hours duration) and included lectures using PowerPoint, interactive content (class discussion), demonstrations with a doll, and case discussion and assessment/treatment demonstrations on two paediatric clients with cerebral palsy.

Outcome Measures

Both Kirkpatrick's reaction and learning levels were evaluated with the Modified Kirkpatrick Questionnaire; in addition, the MSLQs and the Knowledge Questionnaires evaluated Kirkpatrick's learning level.

The Modified Kirkpatrick Questionnaire - The Kirkpatrick website (Kirkpatrick Partners LLC, 2009) provides several examples of questions that can be used to measure all four levels of training evaluation. A set of 18 questions that measured two levels - reaction and learning - was used (Appendix 3). The behaviour and results levels of the model were not evaluated.

The Modified Stages of Learning Questionnaires (MSLQs) - Authors developed and validated the MSLQs (Appendix 4A, 4B and 4C). In summary, the MSLQ for the workshop on adult neurorehabilitation had five questions related to the first scenario and three questions related to a second scenario. The MSLQ for the paediatric workshop had one scenario and six questions. The questions used in the MSLQs each represented a specific workshop learning objective (Appendix 4D). There were nine 'yes/no' items for each question. Each item was tagged to one of the Stages of Learning (i.e., Evaluation, Learning, Gaining experience) (Appendix 4E). Using a classification grid based on the pattern of responses, each participant was classified into a unique stage for each question. The first stage of learning – Scanning - was determined by exclusion (Appendix 4F).

Knowledge Questionnaires - There were two workshop-specific questionnaires based on the learning objectives for the workshops (Appendices 1 and 2). The questionnaires included a 5-point Likert scale (strongly disagree, disagree, neutral, agree, strongly agree) to indicate the learner's level of agreement with

statements directly related to the learning objectives of the workshops. A score from '0' to '4' for each statement was obtained, where '4' was the maximum knowledge score.

Data Analysis

Each workshop was analysed separately. Quantitative data was described using frequencies, medians, and interquartile ranges (IQR). The four Stages of Learning were collapsed into two categories: 1) Scanning/Evaluation; and 2) Learning/Gaining experience. Pre-to-post-workshop changes from the Scanning/Evaluation stages to Learning/Gaining experience stages were evaluated using the Exact McNemar test. Pre-to-post-workshop changes in the Knowledge Score were evaluated using Sig Test for repeated data. Non-responders were not included in the pre-to-post analyses. A significance level of 0.05 was used. Data analyses were conducted using STATA 13.1 (Stata-Corp, College Station, TX, USA).

Ethics

The research proposal was reviewed and exempted by the Behavioural Ethics Board of the University of Saskatchewan, Canada (June 30, 2017). Participants provided written consent to be part of the study.

RESULTS

Sociodemographic Characteristics

Sociodemographic characteristics are included in Table 1. Most of the participants were from Colon (70.6% adult workshop and 100% pediatric workshop) and more than half had studied in Honduras (52.9% adult workshop and 66.7% pediatric workshop). Most were working in a rehabilitation centre/family support organisation (76.5% adult workshop and 86.7% pediatric workshoop) as shown in Table 1. Figure 2 shows participant numbers for each outcome measure, as well as participants who were lost to follow-up. Attempts to contact all participants for follow-up evaluation were made by email and phone. If people did not respond within 3 weeks, they were classified as non-responses.

Table 1: Sociodemographic Characteristics of the Workshop Participants

Variable	Adult Workshop (n=17)	Paediatric Workshop (n=15)
	Me (IQR)	Me (IQR)
Age (years)	33.0 (26-37)	29 (24-38)
Experience working in health sector (years)	2 (1-7)	4 (2-7)
Experience since the highest degree was obtained (years)	4 (1-7)	2 (1-4)
	n (%)	n (%)
Gender		
Women	14 (82.4)	14 (93.3)
Men	3 (17.6)	1 (6.7)
State		
Colon	12 (70.6)	15 (100)
Yoro	3 (17.6)	0 (0.0)
Atlántida	2 (11.8)	0 (0.0)
Profession		
Physiotherapist	6 (41.2)	4 (28.6)
Physicians/nurses	3 (17.6)	3 (21.4)
Education professionals or other non-physiotherapists	8 (41.2)	7 (50.0)
Workplace		
Hospital	4 (23.5)	2 (13.3)
Rehabilitation Centre/ family support organisation, clinics	13 (76.5)	13 (86.7)

Me= Median; IQR= Interquartile Range

Modified Kirkpatrick Questionnaire

In relation to the reaction level of the Kirkpatrick questionnaire, participants found the workshops engaging, relevant and favourable, with over 82% and 87% of responses rating "agree" or "strongly agree" in the adult and paediatric workshops, respectively. Similarly, a high percentage, over 82% and 80% of participants attending the adult and paediatric workshops, respectively, agreed or strongly agreed with the items of the skills, attitude, confidence and commitment components of the learning level of Kirkpatrick's model (see more details in Appendix 4).

Stages of Learning

There were no changes in the MSLQs in the adult workshop. However, in the paediatric neurorehabilitation workshop, there was a change in the number of participants who moved from Scanning/Evaluation stage in the pre-workshop evaluation to Learning/ Gaining experience stage in three different topics, in the one-month post-workshop evaluation. In the questions: "Can you describe the developmental milestones that Jose should have completed up to one-year

old?" (p=0.031), "Can you explain how rehabilitation could improve Jose's motor control?" (p=0.016), and "Can you apply strategies to stimulate the child's motor development?" (p=0.008), the number of participants who moved from Scanning/ Evaluation stage (pre-test) to Learning/ Gaining experience stage (post-test) were 6 out of 7, 7 out of 8, and 8 out of 8, respectively. For the remaining topics, no significant changes in the MSLQs were identified.

Knowledge Score

Table 2 shows that there was a significant change in the pre-to-post knowledge score in the item "I am able to describe the fundamentals of cognitive therapeutic exercise (referring to Perfetti Method) in a client with acquired brain damage". The median score changed from 0.0 (IQR=0.0-2.0) to 3.0 (IQR=1.0-3.0), p=0.016.

Participants who attended the paediatric neurorehabilitation workshop increased their knowledge about concepts of development, learning and motor control (pre-test: 2.5 IQR= 1.0-3.0, post-test= 3.0 IQR= 3.0-4.0, p= 0.016) and milestones of neuromotor development between 0 and 12 months (pre-test: 3.0 IQR=1.0-3.0, post-test: 4.0 IQR= 4.0-4.0, p=0.008).

Table 2: Changes in Knowledge Score Pre-and Post-Workshops

Item	Pre-test	Post-test	p-value[4]
Adult Workshop			
I am able to…	*Median (IQR)*	*Median (IQR)*	p-value
Describe the pathophysiology of acquired brain injury and spinal cord trauma[1]	2.5 (0.0-3.0)	3.0 (2.0-3.0)	0.500
Describe the concept of neuroplasticity[1]	2.5 (2.0-3.0)	3.0 (3.0-4.0)	0.250
Demonstrate the physiotherapeutic assessment in adults with acquired brain injury[1]	2.0 (0.0-2.5)	2.5 (1.0-3.0)	0.375
Demonstrate the physiotherapeutic assessment in adults with spinal cord injury[1]	0.0 (0.0-2.0)	3.0 (1.0-3.0)	0.070
Plan the physiotherapeutic intervention in adults with acquired brain injury and spinal cord injury[1]	2.0 (0.0-2.5)	2.5 (1.0-3.0)	0.219
Describe the fundamentals of cognitive therapeutic exercise (Perfetti Method) in an adult with acquired brain injury[1]	0.0 (0.0-2.0)	3.0 (3.0-3.5)	**0.016**
Apply the proprioceptive neuromuscular facilitation techniques to control the trunk in adults with acquired brain injury[1]	0.0 (0.0-2.0)	2.0 (1.0-3.0)	0.125
Apply proprioceptive neuromuscular facilitation techniques proposed to reinforce the residual musculature in adults with spinal cord injury[1]	0.0 (0.0-2.0)	2.0 (1.0-3.0)	0.125
Demonstrate the physiotherapeutic intervention in a sedentary and bipedal position in an adult with acquired brain injury[1]	0.0 (0.0-2.0)	3.0 (1.0-3.0)	0.070
Paediatric Neurorehabilitation Workshop			

I am able to…			
Briefly describe the embryonic development of the central nervous system[2]	2.5 (2.0-4.0)	3.0 (3.0-3.0)	0.289
Define the concepts of motor development, motor learning and motor control[2]	2.5 (1.0-3.0)	3.0 (3.0-4.0)	**0.016**
Describe the milestones of neuromotor development between 0 and 12 months[2]	3.0 (1.0-3.0)	4.0 (4.0-4.0)	**0.008**
Define the concept of neuroplasticity[3]	3.0 (1.0-4.0)	4.0 (3.0-4.0)	0.188
Apply the principles of intervention selected in children with deficits in neuromotor development[3]	3.0 (1.0-3.0)	4.0 (3.0-4.0)	0.125
Propose a functional adaptation for children with motor development deficit[3]	3.0 (2.0-3.0)	3.0 (3.0-4.0)	0.219

[1]n=8; [2]n=10; [3]n=9; IQR= Interquartile Range; [4]Statistically significant p-values boldfaced

DISCUSSION

Through engagement with community and local Honduran neurological rehabilitation centres, the Network of Rehabilitation Workers of the Americas planned, executed and evaluated two neurorehabilitation workshops for a mixed professional audience in northern Honduras. The workshops had positive effects on the Kirkpatrick Levels of reaction (engagement, relevance, satisfaction) and learning (skills, attitude, confidence and commitment). Positive effects were also found in Stages of Learning and Knowledge questionnaires.

Reaction to the Workshops

Kirkpatrick's first level evaluates participants' reactions to workshops. Most participants were engaged since they agreed that the physical environment of the workshop helped the learning, the workshop was interesting, and most of them also reported commitment to the workshop activities. Similarly, most participants considered the workshop relevant; the material was useful and applicable to their work and client care. In addition, there was a high level of satisfaction. Most respondents agreed that participating in these workshops was worth the time. The positive reaction to the workshops could in part be due to the fact that the themes and the cases were selected following discussions with local health workers who knew the needs and context of northern Honduras. Several training evaluation studies have relied on the first level of Kirkpatrick's model as the only area of evaluation (Morgan & Casper, 2000). The authors in those evaluations considered their results encouraging, even when a positive reaction does not guarantee learning, changes in behaviour, or results (Reio, Rocco, Smith & Chang, 2017). The current study also evaluated learning effects, which is a

unique contribution to this area of research.

Evaluation of Learning

The evaluation of learning was divided into three parts: Modified Kirkpatrick's Questionnaire (dimensions include skills, attitude, confidence and commitment); Moore and Slotnick's Stages of Learning; and finally, the findings of Knowledge questionnaires.

Modified Kirkpatrick Questionnaire - Regarding Kirkpatrick's second level (learning) which evaluates the extent of knowledge, skills, attitude, confidence and commitment (Kirkpatrick & Kirkpatrick, 2016), most participants: 1) reported that they would be able to use what they learned right away (skills); 2) believed their attendance at the workshops would have positive impacts on quality of care, personal confidence, client satisfaction, relations with colleagues, and respect of colleagues (attitudes); 3) felt confident in correctly applying the knowledge and techniques they had learned without harming their clients (confidence); and 4) felt committed to apply what they had learned in the workshops at work (commitment).

Stages of Learning - The MSLQ showed acceptable content validity. Because the scenarios and questions used in the MSLQs were based on the workshop objectives, they can only be used for future workshops that have the same objectives. However, the structure (objectives, scenarios, questions, items) of the MSLQ and the 'yes/no' items themselves could be transferable to classify Stages of Learning related to other workshops having a clinical focus.

No change in the MSLQ was found in the adult neurorehabilitation workshop. However, a significant improvement in the MSLQ was found for three areas in the paediatric workshop: 1) the concepts and processes of foetal development; 2) motor learning and motor control; and 3) the concept of neuroplasticity. These concepts are foundational for the application of rehabilitation interventions; thus, effects in these areas of learning represent meaningful change.

These workshops were brief and intensive and did not include time for direct observation of practical skills. As stated by Moore and Slotnick (2006), "the options accompanying each vignette did not ask how the problems should be handled; rather, the options sought to identify each respondent's educational status or the learner's stage, relative to the problem in the vignette (i.e., scenario)." Assessment of clinical/skill learning is difficult even in the context of formal education (Kogan,

Holmboe & Hauer, 2009) but in the context of workshops of two days or less, it is possible only for extremely systematised instruction such as cardiopulmonary resuscitation training (Makinen, Niemi-Murola, Makela & Castren, 2007). The MSLQs and scenarios were used to help assess the application of knowledge to real life situations, thereby overcoming some of the challenges of measuring the effects of this brief, concentrated format of adult learning.

Knowledge - Participants in the adult neurorehabilitation workshop improved their knowledge in cognitive therapeutic exercise (Perfetti Method). For the participants in the paediatric neurorehabilitation workshop, a significant increase was noted in knowledge about concepts of development, learning and motor control as well as milestones of neuromotor development between 0 and 12 months.

To the best of the authors' knowledge, there are neither any published applications of the Kirkpatrick Model and the MSLQs to neurorehabilitation workshops, nor to the application of these tools in an international collaborative teaching and learning context for health workers. The few studies that are documented using the MSLQs are in the area of medical education and veterinary medical informatics (Moore & Slotnick, 2006); however, these studies used a different approach to the classification of the Stages of Learning (Experience, Learning, Evaluation, Scanning). In addition, only one training evaluation study specific to rehabilitation was found. In this study (McEwen, Szurek, Polatajko & Rappolt, 2005) learning was evaluated after completion of an online module in stroke rehabilitation for 108 occupational therapists, physical therapists, registered nurses, and speech-language pathologists from Canada, which is not comparable with the present study.

Strengths

Rehabilitation practice and continuing education should consider the local context, its needs and practices (Wickford, Hultberg & Rosberg, 2008; Edwards, Wickford, Adel & Theoren , 2011; Wickford & Duttine, 2013). In this sense, the strength of the current study was the collaborative approach. This project brought rehabilitation workers together with local peers and with international partners from Colombia and Canada. Workshop themes were selected by establishing an ongoing dialogue and considering the needs of the Trujillo and Tocoa rehabilitation workers; this mutually beneficial collaboration in all likelihood contributed to the fact that the workshops' curricula were well appreciated.

Future curriculum should be designed to include group activities that foster continuing collaborations including partnership with a local university.

Another strength of this study was that the learning evaluation included different approaches. First, several tools were applied to evaluate the different components of the learning levels. Second, different time-points were used to evaluate learning: before the workshops, immediately after them, and one month post workshops, which allowed for the assessment of changes in learning.

Limitations

Lack of a control group limits conclusions about whether observed changes in knowledge and stages of learning are the result of the workshops, rather than other factors. Second, the study has a high percentage of post-test non-respondents (33%-60%). In addition, the small sample due to the limited number of workers in the region could reduce the power of the study to detect an effect. These factors can also limit generalisability of the results. The findings will be more generalisable to small neurological continuing education workshops developed in collaboration with instructors, community members and researchers.

A major limitation with this evaluation of training effects was that only levels 1 and 2 of the Kirkpatrick model were evaluated: reaction and learning. Evaluations of both behaviour and results were not done. Moore and Slotnick (2006) acknowledge that "documenting change in clinical behaviour is difficult". To evaluate change in clinical behaviour, it would be necessary to directly observe changes in the clinical setting. Implementing rigorous measurement of behaviour change in the clinical practice of workshop participants with heterogeneous professions, formal training, work assignments, and distributed across different centres, would be costly, time consuming and a formidable undertaking. In the absence of evidence of Kirkpatrick's levels 3 and 4, the study cannot imply that the positive effects observed in reaction and learning will translate into changed behaviours or positive results in the clinical environment.

Implications

Based on the results of this study, iterations of the Network of Rehabilitation Workers of the Americas visiting professor programme and workshops held in 2018 and 2019 were designed to maximise opportunities to establish the rehabilitation professions and develop local leadership through: a) incorporating

an active teaching role for Honduran professionals in future workshops, b) establishing further linkages with the rehabilitation and medical professions (including physiatrists, neurologists, nurses, psychologists), c) visiting rehabilitation centres for applied learning and mentorship, d) interacting with local universities, and e) advocating for inclusion of persons with disabilities in all aspects of society.

Historically, capacity building in developing countries has been externally driven (Goldberg & Bryant, 2012). The Network of Rehabilitation Workers of the Americas is a professional, interdisciplinary north-south collaboration focused on rehabilitation capacity building that utilises a participatory approach. The work of the Network of Rehabilitation Workers of the Americas is relevant and timely, and despite its urgent need for strong leadership in rehabilitation there are no other such collaborations in Honduras. This collaboration will be continued to improve leadership and professional capacity needs for stronger health systems and improved outcomes, as well as to alleviate the burden of disease and disability in Honduras.

CONCLUSION

Workshops offered to the mixed healthcare workers in Honduras through a community-engaged international academic network resulted in a positive reaction; acquiring of skills, attitude, confidence and commitment; advanced learning opportunities; and acquisition of relevant knowledge which has the potential to improve quality of care for people with neurological conditions in the northern region of the country. Case-based learning and a supportive peer environment were used during the workshops and were important elements in promoting learning. Future visiting professor workshops will expand on this successful pilot to include more opportunities for applied learning and interprofessional collaboration.

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APPENDICES

Appendix 1: Objectives of the Adult Workshop

Workshop - Neurorehabilitation in adults with acquired brain injury, spinal cord injury, and cerebral vascular accidents. Tocoa, September 8 and 9, 2017. Intensity: 2 hours

(Taller de Neurorehabilitación en pacientes adultos con daño cerebral adquirido y trauma raquimedular)

1) Describe the epidemiology, pathophysiology, clinical presentation of acquired brain injury (cranioencephalic trauma, stroke) and spinal cord trauma

2) Describe the concept of neuroplasticity

3) Demonstrate the physiotherapeutic assessment in adults with acquired brain injury according to the presented problem

4) Demonstrate the physiotherapeutic assessment in adults with spinal cord injury according to the American Spinal Injury Association

5) Plan the physiotherapeutic intervention in adults with acquired brain injury and spinal cord injury according to the needs of the client

6) Describe the fundamentals of Cognitive Therapeutic Exercise (Professor Perfetti Method) in clients with acquired brain injury

7) Apply proprioceptive neuromuscular facilitation techniques (Kabat and Knott) to control the trunk in clients with acquired brain injury (stabilisation, isometric)

8) Apply proprioceptive neuromuscular facilitation techniques (Kabat and Knott) to reinforce the residual musculature in clients with spinal cord injury (rhythmic stabilisation, isometric, repeated contractions)

9) Demonstrate the physiotherapeutic intervention in a sedentary and bipedal position in a client with acquired brain injury using the Bobath concept and motor relearning

Appendix 2: Objectives of the Paediatric Workshop

Workshop - Rehabilitation for children with impaired neuromotor development. Trujillo, September 13, 2017. Intensity: 7 hours

(Taller 2. Rehabilitación en niños con alteraciones del desarrollo neuromotor)

1) Briefly describe the embryonic development of the Central Nervous System

2) Define the concepts of motor development, motor learning, and motor control

3) Describe the milestones of neuromotor development between 0 and 12 months

4) Define the concept of neuroplasticity

5) Describe the major dysfunctions of movement in children with cerebral palsy (for example, hypotonicity, hypertonicity, ataxia, flaccidity)

6) Apply the principles of intervention selected in children with deficits in neuromotor development

7) Propose a functional adaptation for the child with motor development deficit

Appendix 3: Modified Kirkpatrick Questionnaire

A. Reaction Level

Level/Dimensions/Items	Adult Workshop		Pediatric Workshop	
	In disagreement/ Neutral	Agree/Strongly agree	In disagreement/ Neutral	Agree/Strongly agree
	n (%)	n (%)	n (%)	n (%)
1. Reaction Level				
1.1. Engagement				
The physical environment of the workshop helped me to learn	0 (0)	16 (94)	1 (7)	**13 (87)**
This workshop kept my interest	1 (6)	15 (88)	0 (0)	14 (93)
I was committed to what was happening during the workshop	0 (0)	16 (94)	0 (0)	14 (93)
1.2. Relevance				
The workshop material will be useful for my future work with clients	1 (6)	15 (88)	0 (0)	14 (93)
The information in this workshop is relevant and applicable to my work	2 (12)	**14 (82)**	1 (7)	14 (93)
I think the content of this workshop is important to improve client care	0 (0)	16 (94)	0 (0)	15 (100)
I think it will be worthwhile to apply at work what I learned in the workshop	1 (6)	15 (88)	0 (0)	15 (100)
1.3. Customer Satisfaction				
The information I received before the workshop was useful	0 (0)	15 (88)	0 (0)	15 (100)
Taking this workshop was worth my time	0 (0)	16 (94)	0 (0)	15 (100)

Lowest percentages boldfaced.

B. Learning Level

Level/Dimensions/Items	Adult Workshop		Paediatric Workshop	
	In disagreement/ Neutral	Agree/ Strongly agree	In disagreement/ Neutral	Agree/Strongly agree
	n (%)	n (%)	n (%)	n (%)
2. Learning Level				
2.1. Skills				

I will be able to use what I learned right away	2 (12)	**14 (82)**	0 (0)	15 (100)
2.2. Attitude				
If I consistently apply what I have learned, I believe that				
... the quality of care will improve	0 (0)	16 (94)	0 (0)	15 (100)
... my personal confidence will increase	1 (6)	15 (88)	0 (0)	15 (100)
... client satisfaction will increase	1 (6)	15 (88)	1 (7)	14 (93)
... relationships with my colleagues will improve	1 (6)	15 (88)	1 (7)	13 (86)
... the respect of my colleagues towards me will increase	2 (12)	**14 (82)**	3 (20)	**12 (80)**
2.3. Confidence				
I can correctly apply the knowledge and techniques that I have learned	2 (12)	**14 (82)**	2 (13)	13 (87)
I can apply the knowledge and techniques that I have learned without harming my clients	2 (12)	**14 (82)**	1 (7)	14 (93)
2.4. Commitment				
Q13. I am committed to apply what I learned in the workshop at work.	2 (12)	**14 (82)**	1 (7)	14 (93)

Lowest percentages boldfaced.

Appendix 4: Development and Content Validation of the Modified Stages of Learning Questionnaires

A. Methodology

Four physiotherapists on the research team developed two MSLQs, one for each workshop. Six Spanish-speaking experts in neurorehabilitation independently evaluated the MSLQs. The experts' median age was 41 years (IQR=37-45); three were from Colombia, two from Honduras and one from Argentina. Four were physiotherapists and had a Master's degree in neurorehabilitation, one was a physician with a diploma in rehabilitation and one was a physiatrist. The mean of experience working in neurorehabilitation was 8 years (IQR=5-22). The self-reported expertise in adult and paediatric neurorehabilitation was 10 (8-10) and 8.5 (6-10), respectively, on a scale from 0 to 10 (0 was no experience at all and 10 was the maximum neurorehabilitation experience imaginable).

Each of the experts was asked to rate the relevance of the clinical scenarios, the questions, and the items of the MSLQ using the following 'yes/no' question: Do you consider this clinical scenario/question/response scale relevant?

In addition, experts were asked to comment using open-ended questions about how the clinical scenarios, questions or response scales could be improved.

B. Data Analyses

An item content validity index (I-CVI) was calculated for each scenario, question and item of the MSLQ. The I-CVI is the proportion of experts who rate its content as valid (a 'yes' response to the relevance question) divided by the number of experts (Polit et al, 2007). A scale content validity index (S-CVI) was then calculated for the overall questionnaire. The S-CVI is the average of all the I-CVIs of the individual scenarios, questions and response scales. An acceptable S-CVI should be greater than 0.80 (Polit et al, 2007). Comments from the six experts were discussed by the four physiotherapists until consensus was reached. Before using the final MSLQ version, the questionnaire was sent to a local physiotherapist who was asked whether the scenarios, questions, or response scales were understandable. If 'no', she could give suggestions for improvement.

C. Results

The I-CVI of the three clinical scenarios and the nine response scales was 1.0. The

lowest I-CVI was obtained in the question linked to the Cognitive Therapeutic Exercise (I-CVI=0.67) followed by the questions "Can you describe the components of the physical therapy evaluation according to the American Spinal Injury Association for a complete spinal cord injury level T10?" and "Can you apply the technique of repeated contractions (proprioceptive neuromuscular facilitation) to the upper limbs of Mary to facilitate the strengthening of the trunk?", which obtained an I-CVI of 0.83. The I-CVI of the remaining 11 questions was 1.0. The S-CVI was 0.97 indicating evidence of acceptable content validity. After the content validation process, minor suggestions were given to improve the clarity of the wording. The translated final version of the scale can be found below.

D. Clinical Scenarios and Questions of the Modified Stages of Learning Questionnaires

Clinical Scenario: Acquired Brain Injury in Adults
Diego is a 40-year-old man who had a traumatic brain injury as a result of an automobile accident. The lesion occurred on the left side of the brain. There is hemiparesis of the right arm and leg. He is able to sit with someone's help and can lift his arm about 80 degrees for shoulder flexion. He cannot stand without moderate help due to weakness of the right leg and difficulty maintaining balance.
1. Diego's wife wants to know about traumatic brain injury. Can you explain the injury and how neuroplasticity will benefit Diego's rehabilitation?
2. Begin with an assessment. Can you describe the evaluation parameters that a physiotherapist applies in this case?
3. It is necessary to design the intervention plan to improve the balance in the standing position. Can you propose the therapeutic strategies to achieve this goal?
4. Can you explain what the Cognitive Therapeutic Exercise adds to Diego's rehabilitation?
5. It is necessary to improve Diego's postural alignment in sitting posture by proprioceptive neuromuscular facilitation. Can you apply these techniques?
Clinical Scenario: Spinal Cord Injury
Maria is a 22-year-old woman with a fracture of the tenth thoracic vertebra (T10) and a complete spinal cord injury as a result of a motorcycle traffic accident. She is functional in a wheelchair and has proper bowel / bladder management.
6. Can you explain to Maria what the clinical manifestations are of a complete spinal cord injury level T10?
7. Can you describe the components of the physical therapy evaluation according to the American Spinal Injury Association for a complete spinal cord injury level T10?
8. Can you apply the technique of repeated contractions (proprioceptive neuromuscular facilitation) to Maria's upper limbs to facilitate the strengthening of the trunk?
Clinical Scenario: Paediatric Client

José is an 8-year-old boy with spastic diplegia. His legs are affected by weakness and muscle tension in the hips, knees, and feet with contractures causing him to walk on tiptoe. He has lived in a rural area without access to rehabilitation services but has just moved to Trujillo. His family is very excited about the availability of care in the clinic. Both Mum and Dad have arrived at their first treatment session.
1. Can you help Jose's mother understand the problems of her child's movement?
2. Can you describe the developmental milestones that Jose should have completed up to one year old?
3. Can you explain how rehabilitation could improve Jose's motor control?
4. Can you explain to Jose's parents how spasticity affects Jose's movement?
5. Can you apply strategies to stimulate the child's motor development?
6. Can you recommend a functional adaptation for Jose?

E. Clusters of questions in each of three categories: Evaluation (E), Learning (L), and Gaining Experience (Ex)

Yes	No	Stage	Items
O	O	E1	This question is appropriate for me
O	O	E2	There is a solution to this question
O	O	E3	Learning to solve this question will benefit my practice.
O	O	L1	I am taking action to resolve this question
O	O	L2	I am learning the knowledge required to solve this question
O	O	L3	I am learning skills to solve this question
O	O	Ex1	I am applying my knowledge to solve this question
O	O	Ex2	I am practicing effective skills to solve this question
O	O	Ex3	I have confidence in applying my knowledge / skills to solve this question

F. Classification Grid showing the Patterns of Responses that were associated with the four Stages of Learning

	Classification of Stages of Learning			
Number of Items		Evaluation	Learning	Experience
3	Experience	3	3	3
3	Learning	3	3	<3
3	Evaluation	3	<3	<3
0	Scanning	Otherwise		

Reference for this Annexure: Polit DF, Beck CT, Owen SV. (2007). Is the CVI an acceptable indicator of content validity? Appraisal and recommendations. *Research in nursing and health, 30*(4), 459-467.

Emoticons as Self-Disclosure in Social Media and Its Meaning for People Who are Deaf

Eka Bagus Rachdito[1], Z Hidayat[1*]

Communication Department, BINUS Graduate Programme – Master of Communication Science, Bina Nusantara University, Jakarta, Indonesia

ABSTRACT

Purpose: The limitations in communication for people who are deaf or unable to speak are evident. Like other people with disabilities, they too seek to acquire knowledge, search for information and understand its content, but there are barriers to self-expression and self-disclosure. This study provides insights into opportunities for people who are deaf, yet are able to access digital communication technology. It analyses their use of social media and emoticons for messages and communication. Online interaction enables self-disclosure to other people with deafness, as well as to people without disabilities.

Method: The study used a qualitative approach with a phenomenological design. The interpretation of data was carried out with 5 key informants from the deaf community and 12 members of the deaf community, who use social media applications and various types of emoticons for self-disclosure on WhatsApp and Facebook. Selection of various emoticons took place through in-depth interviews, observations, and analysis of the conversations among themselves as well as people without disabilities.

Results: The findings show that the motives for using social media, emoticons, and communication technology are to build online interactions and enable self-disclosure among people who are deaf. The use of emoticons in social media helps people who are deaf to express their feelings towards others, to communicate with their families and build intimate interpersonal relationships, making it easier to get along in their community. The ability to interact and understand social media content and communication technology, in general, depends on their experience and ability to master and give meaning to signs, words, emoticons, and language.

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* **Corresponding Author:** Z Hidayat, Master of Strategic Marketing Communication, Bina Nusantara University, Jakarta, Indonesia. Email:z.hidayat@binus.edu

Conclusion: People with hearing impairment have had significant benefits from using social media and communication technology. Access to information and knowledge about the personal lives of individuals and their communities, through social media, has added cohesiveness within the community of people who are deaf. By using various emoticons, people with hearing impairment can apply signs, words, and symbols to express emotions and feelings. This makes the meaning of a sentence or interaction between individuals more robust and precise, creates stronger messages, and at the same time can be a medium for self-disclosure. However, due to difficulty in distinguishing between messages on social media that may be true or false, people who are deaf tend to feel at times uncertain and confused.

Keywords: *communication technology, deafness, emoticons, people with disabilities, self-disclosure, social media*

INTRODUCTION

People who are deaf are described as a group of people who have some problems in communication, such as limited understanding to recognise spelling and limited ability to speak. They cannot use voice- and sound- technology with ease as their impairment often makes it difficult to produce sounds, articulate words, or speak clearly. In Indonesia, the term "deafness" represents a pathological view, with hearing loss in the medical world being regarded as the result of a disease or damage caused by an accident. From a medical point of view, deafness results from a disorder of the inner ear. "Deafness" is also associated with stigma because it is regarded as medical damage that needs to be normalised. However, the deaf community in Indonesia do not see themselves as having a disability or incapacity. People who are deaf consider themselves as part of a "deaf culture" and do not feel defective or impaired, and surprisingly do not wish to be capable of hearing (Barnett, 2002). Called a linguistic minority group, they build their culture and sign language as they develop and become empowered; this enables them to communicate. Sign language is created to be used in communication wherever individuals have hearing disabilities (Lim, Susiapan & Gopalkrishnan, 2020).

The empowerment of individuals who are deaf is crucial, particularly from the perspective of communication. In order to understand this, one should understand the concept of deafness. According to Munoz-Baell and Ruiz (2000), hearing loss is a complex phenomenon with severe consequences and involves

many factors and problems.

Today, people who are deaf face various challenges in carrying out activities in society. They try to be like other people but face limitations for which social media may become the solution. Social media can unite, can play a role in forming family and friendship networks, and help them maintain long-term relationships. Bharoto's study (2018) stated that among Indonesians, people with disabilities, including people who are deaf, are a vulnerable group who still face various issues in fulfilling their needs. Lack of public awareness about the challenges faced by people who are deaf in terms of accessing information, has a significant impact on their acceptance in society. Many people think that because they cannot hear, they cannot communicate well. Consequently, people who are deaf are perceived to be unable to understand current and new technological developments, such as communication technology.

"The communication methods used by people who are deaf not only depends on their communication abilities but also depends on people with whom they communicate," according to Chang (2014). Often, when people who are deaf are considered intellectually backward, it discourages them from improving their ability to communicate with other people. Deafness requires the ability to communicate, to expose oneself in terms of feelings and emotions, and interact with one's environment, which in many cases means with other people who are deaf. People who are deaf find it more challenging to acquire specific life skills, such as receiving information and expressing themselves clearly and interactively. These challenges make them potentially encounter various problems such as being disconnected from various types and sources of information, having difficulties interacting with other people, and facing obstacles to social and cognitive development (Schick, De Villiers, De Villiers & Hoffmeister, 2007). According to Barnett (2002), people with disabilities sometimes feel insecure because of their inability to communicate fluently, in that they cannot convey exactly what they mean to others; in this case, each individual must be more sensitive in choosing words to accommodate communication with people who are deaf.

Communication Technology and Social Media for People who are Deaf

In society today, communication technology is considered very important to interact, exchange information, and show one's identity. It is a modern trend of social life which has also had an impact on the group of people with hearing impairment. They take advantage of various social media and internet

features to connect with their friends or groups. The internet provides users with consequences such as online opportunities and online risks (Luthfia & Triputra, 2020). New media's transformative and dynamic nature enables them to assist people with disabilities (Alper, 2017). The use of new media in various communication technology tools for ordinary people is commonplace but unique for the people who are deaf, especially if examined in the context of a narrative approach which is very meaningful to help create a healthier climate for community interaction (DeVault, Garden & Schwartz, 2011).

People who are deaf interpret communication technology as advancement in gaining the freedom to communicate and obtain information practically. Maiorana-Basas and Pagliaro (2014) state that as society becomes increasingly dependent on technology, information about the use, preferences and accessibility of devices and services commonly used among deaf and hard of hearing individuals is essential. In the modern era, the evolution in technology and internet innovation caused the emergence of new media and various features such as social media. New media is a form of concept in communication science. According to Dewdney and Ride (2013), new media is the preferred term for various media practices that use digital and computer technology. New media definitions are continually changing and evolving, with some definitions of new media focusing exclusively on computer technology and digital content production, while others emphasise cultural forms and the contexts in which technology was used. Various groups widely use social media for communication in today's modern society because of its many advantages; it is a form of new media evolution, the most effective communication media, which simultaneously uses text, audio, and visual features. It also benefits people with disabilities, such as those who are deaf.

Based on the Ministry of Social Work of the Republic of Indonesia, the data on persons with various disabilities in 2019, especially about people who are deaf, shows a high prevalence rate (https://simpd.kemsos.go.id). Hearing impairment was in the top five categories of the most significant number of groups of people with disabilities in Indonesia. Today, for most people who are deaf, social media can be among the most significant opportunities in their communication and interactions. Ensuring equitable access to technology, mainly to social media features, allows individuals with disabilities to take advantage of the benefits social media can provide, such as collaboration, knowledge-building, information sharing, and advocacy (Cifuentes, Sharp, Bulu, Benz & Stough, 2010). This phenomenon makes it possible for people who are deaf to express themselves or

self-disclose on social media through online interaction. Self-disclosure on social media is necessary for them to convey information about their identity and share what and how they feel with others. Emoticons and other signs can be used.

Self-Disclosure and Online Interaction on Social Media

Human beings are social beings who need interactions with other people. In conducting interactions, an individual will convey information about himself/herself to others. This is related to the concept of self-disclosure for everyone who engages in an interaction. Self-disclosure is an activity to share feelings and familiar information with others. Several studies show that social media is a place to make new friends and participate in communities and, as such, the value of social media is increasingly understood and appreciated (Kim & Kim, 2017). Studies show that social media can connect individuals even from different cultures (Miller, 2016). Interaction through social media can develop and maintain modern relationships (Fan, Jiang, Deng, Dong & Lin, 2020) and increase self-esteem (Hughes, Champion, Brown & Pedersen, 2021). Social media can also help to know how people who are deaf show their feelings and the obstacles they encounter. It is regarded as an essential medium that affects interaction and self-disclosure.

Self-disclosure and online interaction on social media are not enough to replace the spoken word. People who are deaf experience a certain weakness in interpreting words. This can be overcome with the help of additional visuals or symbols in the form of emoticons. Dresner and Herring (2010) state that the term "emoticons" - short for "emotional icons" - refers to graphic signs, such as smiling faces, that often accompany computer-mediated textual communication. The visual is most often characterised as an iconic indicator of emotion, conveyed through communication channels parallel to linguistic ones.

Objective

Disability is not just a person's lack of body structure or function (impairment) but relates to the interaction of the individual with the impairment and social and cultural structures. This study recognises persons with disabilities as people who are part of a group of people with a high level of cohesiveness (Oliver, 1990).

This study aims to analyse the use of social media - WhatsApp and Facebook - among people with hearing impairment in Indonesia. It aims to determine

the effectiveness of social media as a medium for self-disclosure and online interaction among the deaf, and to find how far people with hearing impairment are able to understand the meaning of content they receive on social media.

METHOD

Study Design

A qualitative approach was used to analyse individual and social conditions in groups or communities of deaf people. A phenomenological research design was used to collect data from individuals who are deaf, about their everyday life experiences in their communities through social media and communication technology interactions. Qualitative data was collected through in-depth interviews between September and December 2020.

Study Participants

The key informants in this study were five Indonesian people with hearing impairment, who are coordinators of deaf online communities throughout the country. The key informants (Agu, male, 65 years; Sat, male, 60 years; Adi, male, 58 years; Bro, male, 60 years; and Set, male, 45 years) represent about 98 coordinators in various cities and provinces. Key informants and community members also use social media - WhatsApp and Facebook - to interact and move their community. As coordinators of the deaf community, key informants answered the same questions in the in-depth interviews directly with researchers and through WhatsApp calls and WhatsApp video calls.

In addition to key informants, twelve members of the deaf community were interviewed (Lau, female, 45 years old; Jun, female, 50 years; Bam, male, 31 years; Asi, female, 37 years; Her, male, 41 years; Rio, male, 31 years; Ram, female, 28 years; Muh, male, 29 years; Gal, female, 47 years; Eka, female, 27 years; Ali, male, 22 years; and Nel, female, 20 years). The twelve participants were active on WhatsApp Groups and Facebook. The selection of participants was based on how active they were on social media, either in providing comments or responding to issues discussed by the community.

Ethical Considerations

As informants for this study, the personal identities of all participants are

protected. Due to ethical considerations, abbreviation is only given with a three-letter pseudonym to maintain privacy, and this decision is with the consent of all participants.

Data Collection

Data was collected through in-depth semi-structured interviews with all participants, analysis of social media and news documents, and field observations. Semi-structured interviews were used to ensure general consistency throughout the interview process (Kvale, 1994; Doody & Noonan, 2013). Face-to-face interviews were conducted and took place through WhatsApp calls and WhatsApp video calls. The interviews lasted between 30 - 45 minutes, and were recorded for transcription purposes. Issues were raised pertaining to the use of social media in interacting and searching for information and forming interpersonal relationships with fellow members who were deaf or with ordinary people. Both key informants and informants were asked six main questions related to relationships. Probing questions were used to gain insight into the role of social media in communicating personal feelings and building romantic relationships. The questions were almost the same as those used in interviewing the coordinators but were more specific to the individuals' experience and ability to interpret messages from various emoticons representing their feelings and inner mood.

In-depth interviews covered their daily life experiences. The questions asked in the in-depth interviews included: "what social media was used", "how was it used", and "how the application helped in receiving or understanding information". Researchers also asked: "how social media helped in interpreting conversations and structuring subsequent conversations", "how emoticons were selected and used", and "how the emoticons helped in representing thoughts and feelings". Some questions were asked about private life, such as "how one interacts with each other online" and "how one conveys feelings of love, worry, discomfort, hate, or being truly in love with someone".

In addition, the analysis of documents resulting from community conversations on WhatsApp and Facebook were used to triangulate findings. For several months, intensive observations of the deaf community were conducted to obtain facts about the use of online media in relation to real life. Other secondary data was obtained from audio archives, video recordings, written documentation, and supporting literature.

Data Analysis

This phenomenological approach was carried out to avoid researcher subjectivity, bracketing, or epoché process, because phenomenology seeks to enter the world of participants' lives, reveal individual experiences, and identify the inherent and unchanging meaning of an item or idea under scrutiny. According to Moustakas (1994) and Marsilio (2017), researchers must eliminate prejudices about the phenomenon to truly understand the participants' experiences of using social media, in this case by people who are deaf. The researcher writes down his experience of the phenomenon to identify possible prejudices. This preconception reflects how researchers positively experience using social media to interact and share meaning in the deaf community.

The primary data in this study are conversations on social media platforms -WhatsApp and Facebook. Additional data came from interview transcriptions of five key informants and twelve other participants. The phenomenological data analysis procedure was carried out based on the guidelines presented by Colaizzi (1978): first, analysing social media content; second, reading and rereading the transcript. This process ensures the researcher has an overall understanding of the essence of both. The next step is to extract essential documents and statements from each transcript related to the phenomenological experience. Social media data and significant statements describe the essence of individual experiences in the community from participant interview responses. The meaning of the conversations and the crucial statements were categorised into themes or dimensions of analysis.

RESULTS

Demographics

The participants, both key informants and informants, consisted of 6 females and 9 males. Their education levels were junior high school, senior high school, vocational, and undergraduate, while the community leader had a Master's degree. The age range of participants was from 18 to 65 years. All of them were Indonesians of various ethnicities. Some were from the community of coordinators in various cities in Indonesia with around 110 local leaders, and the local deaf community in Greater Jakarta with 74 members. The observations took place in various cities or provinces like Jakarta, Banten, Bandung, Yogyakarta, Solo, Semarang, and Bali. Due to time constraints, it was not possible to obtain

information from participants across all provenances.

The Shared Experience

This study analyses conversations on WhatsApp and Facebook that were considered very important for people who are deaf to express themselves. These conversations give insight into formal and informal conversations and add to our knowledge and understanding of the use of these social media platforms. WhatsApp and Facebook, and communication technology in general, have helped people who are deaf to search, find information, interact, and share knowledge and experiences with fellow people with disability and others. Social media also cements friendships and networks of family or friends who have been separated, by enabling them to find out about those whom they have not seen for a long time. Valentine and Skelton (2008) state that social media is a source for sharing (new) knowledge, making friends, discussing, and interacting with one another.

The uniqueness of the individual physical state and the deaf community associated with communication technology is significant in their lives. Social media consumer experience was analysed by dimensions of "what" and "how" as phenomenological textual and structural components (Yuksel & Yildirim, 2015). The "what" dimension relates to the textual aspects such as the object of the action or what has been done, while the "how" dimension relates to the structural action of experience.

Two of the community coordinators stated:

> "*Social media, especially Facebook and WhatsApp, provide a lot of access for us as people with hearing impairments. We can communicate like people with perfect bodies. We can talk, even if only with text and visuals. We can feel each other's feelings through video calls, just pictures without sound, and get a sense of any news by reading text. We are used to shared experiences in the consumption of news, information, and entertainment. We get to know more about organisations' announcements to the deaf community or the communities in other areas at domestic and overseas levels. Individually, and as a community, we learn a lot from each other, especially with the use of sign language*" (Agu, male, 65 years, private interview).

> "*WhatsApp and Facebook gave me much information quickly that I usually do not get right away. I like learning content such as religious issues, information on political news at home and abroad. All these shared experiences support my*

work as a Sign Language teacher at school" (Adi, male, 58 years, private interview).

The deaf community welcomes and enjoys the accessibility of social media as an alternative because they have been excluded from easy access to conventional media for a long time. Their delightful individual experiences are shared with the community. People who are deaf celebrate each other and make social media a home for conversation and friendship. Individual or group experiences are packaged as messages and passed on through channels to other people who are deaf, and to the broader community.

Understanding and Responding to Social Media Messages

For media users, a problem with one of the five senses, namely hearing, certainly interferes with the process of receiving and understanding the content of messages. After receiving the message, the decoding process continues to the encoding process of replying to the message's contents. Deaf users mobilise symbols to convey the meaning of letters, words, and sentences, and symbols enable them to understand visuals or audio-visuals. Hence, various social media features are beneficial in both processes.

People with hearing impairment need to understand the use of all kinds of features and content in order to maximise the use of social media. The ability to use features and message content from the content they get on social media is the key to their success in using social media to reach other people with hearing impairment. When there is a message of any content on social media, it encourages people with hearing impairment to respond to such messages. With the differences they experience, people who are deaf influence each other to understand existing content better.

Every person with hearing impairment has his/her own way of understanding content that is considered difficult to follow, such as questioning the meaning of messages received from other people. They usually ask their friends who are deaf or their families to verify their interpretation. Another way to understand the meaning of a message or content is with the help of technology, such as the Google search engine. The independence of deaf individuals was reflected in their ability to understand social media messages by searching for the meaning on Google. They can quickly type in keywords they do not understand, and instantly search for the meaning of messages or terms unfamiliar to them. Often

people who are deaf have difficulty identifying each word or language, and understanding its contents.

> *"I am often confused and do not understand many terms or words that appear in written conversations. The solution is, I always look for information from the dictionary provided on Google. This method is more efficient than asking other people, which may take more time"* (Nel, female, 20 years, private interview).

> *"... The difficulties that I often experience, for example, I find many local languages spoken by my friends on WhatsApp and Facebook. Many idioms are new to me, and I feel foreign in the conversation. Then I ask my family and friends, but they also don't know the meaning"*(Ali, male, 22 years, private interview).

Based on the two statements above, it can be said that for people who are deaf it is necessary and essential to understand the exact meaning of each word and language – which is considered difficult – that they receive on their social media. Another obstacle in identifying content is the meaning of images and videos on social media. People who are deaf will focus on writing or texting images and videos to determine the meaning of the message content in identifying an image and video. Deaf people – as much as anyone else - will see signs and cues implied in the content of images and videos.

> *"[...] if the picture or video is difficult to understand, for example, a video with sound, then I ask people like my family to explain the situation or meaning"* (Her, male, 41 years, private interview).

People who are deaf will not understand statements, pictures, and videos that are not supported by text explanations or sign language but, for instance, explain issues with voiceovers. They will consequently become less interested.

Furthermore, people who are deaf will better understand the content received from other people who are deaf and respond to it based on their perspectives, which can often be the same. Based on observations on the WhatsApp social media group of people who are deaf, it is clear that they prefer to respond to image and video content on social media. Exciting and easy-to-understand image and video content will be responded to or commented on by others in the same WhatsApp social media group or shared with different deaf groups. It is known that people who are deaf will be more familiar with social media content that is easy to understand and supported by text or sign language. The meaning of

explicit and implicit messages received from content that meets the above criteria will be well understood. When deaf persons see an image or video content on social media, they will question whether it has socially essential value or is just entertaining. Various responses on video content were found among deaf people, including responding with emoticons, with opinions, and with questions related to the content they received. During the in-depth interviews deaf people indicated that they could appreciate excellent video content.

The Use of Emoticons

When interacting, the effect of voice and tone, sound or paralanguage, is significant in deepening the meaning of words in conversation. People who are deaf miss these crucial aspects of communication. The world they experience is quiet and still. Unless there is a representation that reflects the atmosphere in which the conversation took place, the use of emoticons by people with deafness is significant to give soul to every expression of thoughts and feelings between individuals in the community. They want to share happiness, sympathy and empathy with people who face the same problems in everyday life.

In using social media everyone has a purpose, such as sending messages, reminders, and expressing their feelings to others. Likewise, people who are deaf build communication with other people who are deaf in order to exchange messages, information, share news, and share happiness, with entertainment content as a form of interaction and self-disclosure. The Schlosser (2020) study concluded that a person's impression of an online persona does not preclude revealing facts about themselves. A person can share facts about himself/herself if those facts reflect his/her situation in a positive way. The interviews and observations show that people who are deaf interact and self-disclose on social media more than through face-to-face interaction. Visual aids were used in several ways, such as uploading photographs and videos of personal activity content, citing, sharing news links, and responding to or commenting on their social media content, WhatsApp and Facebook. Self-disclosure with the help of emoticons on social media by people who are deaf is one way for them to share feelings and information in close relationships.

> *"The pictures I upload will tell a lot more than if I write long words. My expressive photos are for my friends to see. That is why I often post photos or videos of personal activities to WhatsApp or Facebook groups for friends to share. I can see, comment, and get attention. I need responses from people around me*

through social media" (Ram, female, 28 years, private interview).

This shows that self-disclosure on social media can occur by presenting or sharing information about themselves with other people who are deaf, as they want to get feedback or recognition. This phenomenon shows that the higher the frequency and depth of personal activities shared on social media, the better the self-presentation and recognition from the environment (Seidman, 2013).

> *"I can understand and interpret the messages shared by my fellow deaf friends on social media. Besides, I like sharing photos and I also reply to friends who post on WhatsApp. Visual content and comments are usually to laugh about or make fun for hilarious discussions. There are lots of comments there, and we love the visuals and emotions that come with it"* (Asi, female, 37 years, private interview).

People who are deaf also communicate directly in their communities through various features of each social media application, such as chat, WhatsApp calls, and video calls or live streaming to share the factual situation experienced in real-time. They interact directly with other people who are deaf.

> *"I always interact with my friends, and a group of community friends follows me to watch the situation without sound through live streaming chat and video call features. However, if I do not know the person, then I do not answer in sign language. This silent video is easy to understand in our community"* (Bam, male, 31 years, private interview).

Based on interviews and observations in the field, it becomes clear that social media is an essential medium for interaction between deaf people. Chat is profound in meaning if accompanied by emoticons and is easier to understand and get other people to empathise. This feature encourages deaf social media users to communicate their feelings more expressively and creates emotional bonds in interpersonal communication.

Figure1: Online Interaction Concept on Social Media and Emoticon Use
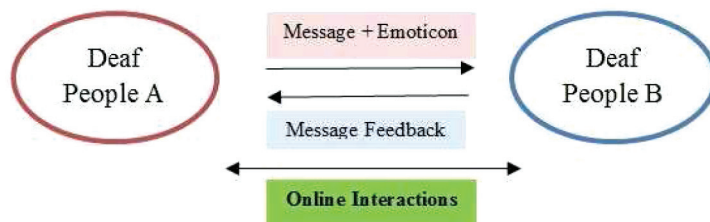
As illustrated in Figure 1, communication requires an encoding and decoding process to take place. In encoding, the originator of the message conveys verbal and visual messages, choosing the right words and emoticons to reinforce meaning. The selection of emoticons in social media requires accuracy on the part of the sender because there are many variations. Meanwhile, in the decoding process, the recipient of the message also does the same thing. Emoticons are very meaningful for people who are deaf to strengthen meaning as a substitute for paralanguage, human voices, or sounds they cannot hear. Inserting symbols that represent the person's emotions during the exchange of messages evokes other interpretations among people who are deaf. During the interviews, two deaf informants mentioned some of the emoticons they used most often in social media, such as chatting or interaction (Provine & Emmorey, 2006; Provine et al, 2007).

Table 1: Responses to Emoticons Used in Online Interactions among People who are Deaf

Question Theme A-5	Deaf Informant 1 Statement	Deaf Informant 2 Statement
Would you please explain the emoticons you most often used as online interactions on social media use?	*"The emoticons that I often use in the social media interaction are likely:* 🤣👍😀😄😫🧑✅😎💤😛 *"*	*"…emoticons that I often use in social media interaction:* 🤣😭😂🤭😄🥴👍🙆🙇 *"*

Emoticons are inserted to represent feelings of pleasure, pain, sadness, disappointment, anger, or happiness. However, emoticons are also used to strengthen the expression of the text messages conveyed on social media. Due to their limitations, people who are deaf have difficulty displaying chat expressions in a text on social media. Emoticons are a valuable feature for them to show how they feel and be appreciated.

> *"… Frequently, I receive messages that disappoint or irritate me in my heart, but usually I just read and do not comment much and do not show an angry emoticon to show that I do not like it. Maybe it is because I am old, unlike young people who are more expressive. However, there are three emoticons that I often use to show disappointment…"* (Sat, male, 60 years, private interview, showing the chat, presented in Table 2).

"I show myself happy and laughing at my friends and relatives through funny videos from YouTube or videos from me. They make funny comments and laugh, reply with laughing emoticons, big smiles, and "hahaha so funny". Some of the emotions that are often used when I show a sense of humour and laughter…" (Jun, female, 50 years, private interview, showing the chat on her Smartphone, presented in Table 2).

"I showed my affection and happiness, especially to my wife and children when I lived abroad for six years, through private conversations and photos of my activities in Hong Kong on WhatsApp and Facebook. I replied to my family with emoticons of love, hugs, longing, warmth, and crying to show that I miss them…" (Agu, male, 65 years, private interview, showing his chat and Facebook with some emoticons that are often used to show nostalgia and love, presented in Table 2).

Table 2: Responses to the three most used Emoticons by People who are Deaf

Participant	Function reinforces Meaning	Choice of Emoticons
ISatri, male, 60 years	To show disappointment	😖🧑😔
ISatri, male, 60 years	To show sadness	😭😥😞
JunSe, female, 50 years	To show sense of humour	😊😄🤣
AgSu, male, 65 years	To show nostalgia and love	😊😍❤️

The use of emoticons should be based on the emotions felt at the time. Therefore, if used appropriately, there will be no misperceptions by other people who are deaf.

Barriers to the Use of Social Media for People who are Deaf

Based on observations and interviews conducted among people who are deaf, several obstacles were found in their use of social media to interact with other people like them. One barrier was poor language skills in their mother tongue and in foreign languages which other people may know. The development of language skills is not the same for deaf people as for people with hearing, causing possible gaps in communication.

".... but I still have a problem because of weakness in vocabulary. I found using WhatsApp and Facebook very helpful. However, the regular people use high language with new words which I do not know the meaning of, so it is difficult

for me to understand" (Gal, female, 47 years, private interview).

"... As a deaf person, I also face problems with other people who are deaf who like to reply or respond to chats on WhatsApp for a long time. Another problem on Facebook is that I often encounter a lot of gossip or hoaxes about all kinds of information continuously in a short time, so it makes me confused, and I have difficulty understanding what is happening in the outside world"(Ali, male, 22 years, private interview).

Based on the experiences of deaf people, this study found three obstacles: 1) inadequate language vocabulary; 2) problems in understanding the meaning of the message; and 3) disturbance due to the flood of information and hoax content on social media. Fake news has become a social issue mainly due to the increased use of social media (Tuteja et al, 2020). The speed with which it spreads without being verified is incredible. This type of information, communicated regularly on social media, makes it difficult for people who are deaf to interpret words considered unusual, including (new and unfamiliar) foreign words.

"I solved the problem by increasing my knowledge of vocabulary and difficult terms that I did not know by searching in a dictionary App or Google and asking questions to my family. Finally, I learned a lot about language and civilisation through social media" (Set, male, 45 years, private interview).

"When I find a problem with social media content, I try to solve the problem by making a video call to the person who uploaded the content. If there is a hoax, I do not know if it is fake news or not. However, I do a news search with the same or similar keywords to reply and provide facts in the comments section or post it for knowledge sharing" (Ram, female, 28 years, private interview).

Deaf individuals and communities show that they can adapt and learn to use communication technology, especially social media, to cover their shortcomings. Like people with hearing, people who are deaf use Google search engines or online dictionaries as libraries for learning. Every minute is a learning moment for them. People who are deaf will trust the information obtained by confirming its truth with a trusted and reliable source or person. As stated earlier, language and signs which people who are deaf do not commonly use are challenging to understand. Therefore, they need to clarify their uncertainty about the meaning of text and signs to ensure their understanding is correct.

DISCUSSION

This study indicates that communication technology, especially social media, has helped people who are deaf to better access information, enjoy new forms of entertainment, and develop and maintain networks among other people with hearing impairment. Online communities are formed faster and more cohesively with an intensive communication process between deaf and ordinary people. Social media such as WhatsApp and Facebook are essential communication channels for people who are deaf to express themselves. The results of this study are in line with the findings of Sweet et al (2020) where persons with disabilities use social media features to build online communities and obtain information. Thus, the richer the social media features with various emoticons and visual elements, the more opportunities for people who are deaf to achieve mindfulness when interacting within and outside their community.

The lessons of this study, which focuses on the importance of communication technology in the daily life of people who are deaf, were also stated by McAleer (2006) who highlights the importance of effective communication with people who are deaf. People who are deaf need sign language to get along with other people like them and with ordinary people. The deaf community has people who can overcome obstacles in communicating and interacting. They are mentally and physically healthy except for hearing impairments. Communities need capacity building, including the use of communication technology such as social media applications. This implication aligns with Nikolaraizi and Makri's (2004) findings, which mention the importance of empowering people who are deaf by promoting social awareness of their existence. The limited ability to communicate with people who are deaf and provide feedback requires a solution with social media (Hornakova & Hudáková, 2013). This finding is a solution in the hospital environment, especially in daily life and life at home. People who are deaf should express their needs, wants, feelings, and opinions in communication with healthcare professionals. The same findings, but specifically in the context of client care, were also presented by O'Halloran et al (2008) that people with communication disabilities are at risk of not communicating effectively with healthcare providers. Therefore, it must be done with a narrative approach. Moreover, the findings of the current research propose social media as a channel for writing narrative messages that are easy to understand in hospitals, residential homes, and peer group or community relationships.

According to a recent study (Guimarães & Fernandes, 2018) social media

is significant for the needs of the deaf to find information in their daily lives. Information deemed necessary by people who are deaf includes original messages from their friends and conveyed by their community, delivered in a language they can understand together. Such communication is called Sign Language. However, sign language communication is very expressive, and facial expressions can be misinterpreted (Hasanbegovic & Kovacevic, 2018).

The findings of this study indicate that people who are deaf have limitations in understanding the meaning of messages, especially from unfamiliar words, due to a lack of vocabulary. However, they quickly learn to find solutions through the Google search engine which provides dictionaries of various languages. The research results reinforce Okuyama's (2013) findings, which show that deaf adolescents adopt various characteristics of English-textism. The unique characteristics of short messages among deaf adolescents were used to extend the structural transfer of sign language in which they interact and communicate. Therefore, solid reading and writing skills are essential if deaf or hard-of-hearing adults wish to take advantage of today's communication technologies. (Toofaninejad et al, 2017). This study also strengthens the findings of Maiorana-Basas and Pagliaro (2014) which state that the use of technology among deaf children, youngsters and adults is essential. Likewise, previous research by Dresner and Herring (2010) considers an analysis based on broader questions about language, body behaviour, and text. Physical sign language needs to be expanded in visuals on social media to confirm meaning sent by communicators to receivers (Young et al, 2019). Vocabularies of people who are deaf were continuously enriched by relying on the internet or explanations through online and offline peer groups. According to Lucas and Valli (1989), the lack of language contact is a significant sociolinguistic problem in the deaf community and should be reduced through shared experiences in the online social media communities.

CONCLUSION

People with hearing impairment who use social media to interact and find information are unique from a communication perspective. They become involved in various forms of entertainment, and build a network of friends by forming a community. Through the various features of social media, such as text messaging, image sharing, video calls, and live streaming, social media is an essential channel of communication in the daily lives of people who are deaf.

Social media has given people who are deaf a lot of confidence because they can

see, follow, and monitor the outside world through access to online platforms. Social media has added to improved cohesion in the community of people who are deaf and people with disabilities.

People who are deaf apply signs, words, and symbols to express their feelings by using various emoticons. With the advanced use of social media, the meaning of a sentence or the interaction between individuals and groups becomes more robust and precise. Social media with opportunities to use emoticons, in particular, has become a medium for self-disclosure.

People who are deaf may not be able to identify a message in every word, sentence and language. It may be difficult for them to understand some content posted on social media. They also have difficulty in sorting and understanding the meaning of untrue or hoax messages in social media content and contrasting perceptions may lead to confusion and miscommunication among them. A solution to this problem is to ask family members or close people to translate and share the true meaning. Another solution is to look for the meaning of the language in online dictionaries. Therefore, it is necessary to educate people who are deaf to receive messages in the language with which they are familiar.

Due to their limited experience and knowledge of language used by people with hearing, deaf individuals and communities use the internet and communication technology in general, to learn and to improve their abilities, especially to build their vocabulary.

People who are deaf must also have intrinsic motivation to improve their ability to understand words and language in communication. They use sign language and emoticons when displaying self-expression and self-disclosure on social media.

It can be assumed that in the study sample, people who are deaf were more confident in expressing emotions in their messages because of the interview questions. Emoticons have an essential meaning for them, and the selection of emoticons that match the content of the message must correspond to the feelings and emotions at the time. If this is ignored, there would easily be a misinterpretation of messages by the person who is deaf.

Limitations

The limitation of this research is that the number of communities observed was

limited to Jakarta, the capital city of Indonesia. However, given the context of an archipelagic state, communities, cultures and habits – among others - can vary widely across islands or regions. Participants were also limitedly recruited by selecting coordinators who are primarily deaf senior individuals and Indonesian deaf activists. In the future, research needs to involve more people who are deaf and have experience in different forms of social media and other communication technology, using a more multidisciplinary approach and methodology.

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The Effectiveness of Community-Based Interventions in Improving Activities of Daily Living and Quality of Life Outcomes in Persons Living with Stroke: A Systematic Review

Raymond Tosoc[1,3]*, Rolando Lazaro[1,2]

1. University of the Philippines, Manila, Philippines
2. California State University, Sacramento, USA
3. Lyceum of the Philippines University – Batangas, Batangas, Philippines

ABSTRACT

Purpose: Despite the growth of literature regarding community-based interventions (CBI) in low- to middle-income and high-income countries, its effectiveness in improving outcomes related to activities of daily living (ADL) and quality of life (QOL) in people with stroke is inconclusive. This systematic review compared the effectiveness of community-based interventions with the usual or hospital-based treatments in improving ADL and QOL outcomes in this population.

Method: Four databases were systematically searched from inception until December 31, 2020, for relevant experimental studies from high-income and low- to middle-income countries that compared CBI with the usual/hospital rehabilitation on outcomes related to ADLs and QOL in clients with stroke. Results: All the 10 experimental studies that were included came from high-income countries (Italy, United Kingdom, South Korea, Canada, and Australia), involving 1575 participants (806 males, 656 females, 113 not classified) with age range from 22-103 years. Seven articles measured ADL performance, and 10 measured QOL. Results indicated that CBI generally demonstrates improvement in ADL and QOL values similar to usual or hospital-based care. There was wide variability in the interventions described and the outcome measures used for both groups. Risk of bias assessment revealed issues with randomisation, blinding and follow-up. Stroke-specific baseline characteristics such as length of time since diagnosis and laterality varied considerably in all of the studies.

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*   **Corresponding Author:** Raymond Tosoc, University of the Philippines, Manila, Philippines.
    Email:rmtosoc@1pubatangas.edu.ph

Conclusion and Limitations: CBI did not demonstrate significant difference in improving ADL and QOL outcomes for people with stroke compared to usual care, possibly due to the high quality of rehabilitation services existing in the countries where the studies took place. There is a need to use standardised outcome measures and interventions to ascertain these outcomes.

Key words: community-based intervention, community-based rehabilitation, activities of daily living, quality of life, stroke rehabilitation, rehabilitation

INTRODUCTION

Stroke or cerebrovascular accident (CVA) is an acquired brain injury resulting from blockage or rupture of associated blood vessels in the brain. The condition can lead to complex impairments in physical and cognitive functions, resulting in restrictions in an individual's ability to perform basic activities of daily living (BADL) or instrumental activities of daily living (IADL) (Desrosiers et al., 2005; World Health Organisation, 2002). Environmental constraints such as lack of access to community services result in limited participation, feelings of abandonment and social isolation (Norrving & Kissela, 2013). Individuals living with stroke also experience depression (Norrving & Kissela, 2013; Tang, Sun, Pang, & Harris, 2018) and reduction in their perceived quality of life (QOL) (Desrosiers et al., 2005).

Stroke is the third leading cause of disability worldwide (Feigin, Norrving, & Mensah, 2017). The age-adjusted prevalence rate for stroke has increased to 299.1 per 100,000 people for ischaemic stroke and 116.6 per 100,000 people for haemorrhagic stroke globally, which is nearly double their value since 1990 (Feigin et al., 2015). In terms of years lived with disability (YLD) which is the health loss brought about by non-fatal conditions (Institute for Health Metrics and Evaluation, 2019; Mokdad et al., 2018), the age-standardised YLD rate percentage change in people with stroke increased by11.2% from 2007 to 2017 (James et al., 2018). This increase has been attributed to the continued progress in medical care for people recently diagnosed with stroke (Brainin, Teuschl, & Kalra, 2007; Gorelick, 2019; Muka et al., 2015; Wang & Langhammer, 2017). The global lifetime risk for stroke however was predicted to increase from 22.8% in 1990 to 24.9% in 2016 (Gorelick, 2019) due to population growth, ageing and unhealthy lifestyles (Ezejimofor et al., 2016; Yan et al., 2016). Therefore, disability related to stroke is steadily becoming an epidemic and the number of cases will rise further in the years to come.

Stroke is one of the main causes of overall disease burden in both high-income countries and low-to-middle income countries (HICs and LMICs) because of the increasing number of people living with stroke-related disability (Thrift et al., 2014). It is therefore important for countries to focus on minimising the resulting disability to reduce their economic burden. Multidisciplinary physical rehabilitation, in conjunction with medical care, has been shown to improve stroke-related functional outcomes (Langhorne, Bernhardt, & Kwakkel, 2011; Teasell, Foley, Hussein, & Cotoi, 2018). Organised multidisciplinary stroke units have been shown to significantly reduce death or dependency outcomes (odds ratio = 0.74; 95% confidence interval = 0.61 – 0.90; p = 0.002) (Stroke Unit Trialists' Collaboration, 2013). This approach to stroke rehabilitation is commonly used in HICs and is costly to administer. A client in the United States spends an average of 8,218 US dollars for post-acute rehabilitation (Agency for Healthcare Research and Quality, 2019). This trend of high-cost physical rehabilitation is also consistent among other developed countries, and consequently denies access to individuals who cannot afford it.

LMICs face a much greater challenge in setting up stroke units due to lack of specialists, facilities, and other system-level barriers (Bernhardt, Urimubenshi, Gandhi, & Eng, 2020; Bettger et al., 2019; Yan et al., 2016), resulting in limited availability of effective rehabilitation services (Bettger et al., 2019; Gimigliano & Negrini, 2017; World Health Organisation, 2019; Yan et al., 2016). The cost of travelling to rehabilitation facilities makes the service even more burdensome for people with stroke and their families. In one Malaysian study, the average total cost for outpatient rehabilitation services for the first three months was 547.10 US dollars, which is already a third of the client's combined average monthly income for three months (Hejazi, Mazlan, Abdullah, & Engkasan, 2015). A similar situation can also be inferred in the Philippines where 55.8% of health expenditures are out-of-pocket payments (Navarro, Baroque, Lokin, & Venketasubramanian, 2014; Philippine Health Insurance Corporation, 2014; Wong et al., 2017). Lack of access to affordable rehabilitative measures has been reported to result in decreased quality of life in people post-stroke (Choi-Kwon, Choi, Kwon, Kang, & Kim, 2006; Mahesh, Gunathunga, Jayasinghe, Arnold, & Liyanage, 2018). These challenges also make the burden of having stroke higher in LMICs than in HICs (Abegunde, Mathers, Adam, Ortegon, & Strong, 2007; Navarro et al., 2014; Yan et al., 2016).

The prohibitive cost and limited access to conventional stroke rehabilitation

has resulted in the development of other approaches to narrow the gap. One of these is to bring the treatment strategies into the home or community of people living with stroke; this is known as community-based intervention (CBI). CBI is delivered either to a set place within the community or at the residences of people with disability, with a single person or a group receiving the service at a time (Iemmi et al., 2015; Liu et al., 2020; Ryan, Enderby, & Rigby, 2006). CBI has been developed in both LMICs and HICs to provide people living with stroke continued rehabilitation services after discharge from hospital care, to augment limited healthcare services, and to promote strategies for the prevention of certain conditions (Iemmi et al., 2015; Johnson, Bird, Muthalib, & Teo, 2020; Magwood et al., 2020; Mannan et al., 2012; Yan et al., 2016).

CBIs are used by the government, health institutions and professionals, case managers or community workers (Bettger et al., 2019; Iemmi et al., 2015; Johnson et al., 2020; Mannan et al., 2012; Ryan et al., 2006). When community workers are involved, they usually undergo training prior to delivering the interventions (Jansen-van Vuuren & Aldersey, 2019; Mannan et al., 2012).

Community-based interventions in both LMICs and HICs are evolving; many studies describe various strategies and techniques being implemented, especially in stroke rehabilitation (Graven, Brock, Hill, & Joubert, 2011; Iemmi et al., 2015; Magwood et al., 2020; Yan et al., 2016). While many of the interventions designed for addressing the healthcare needs of people living with stroke are expected to be more evidence-based, specialised and expensive in HICs due to better healthcare systems, CBIs are not necessarily expensive as these are commonly developed to improve access to these services by stroke survivors (Jeong & Kim, 2007; WHO & World Bank, 2011). In fact, some of the CBIs developed in high-income countries have found their way into low- and middle-income countries. An example of this is early supported discharge (Langhorne & Widen-Holmqvist, 2007) which has been implemented in India and China (Yan et al., 2016). Inexpensive CBIs developed in either LMICs or HICs have been instrumental in providing people living with stroke the means to access their healthcare needs, especially when provided within the context of community-based rehabilitation (CBR).

However, very little is written about the impact of CBI delivered within the CBR approach on the performance of Activities of Daily Living (ADL) and QOL of people living with stroke (Cleaver & Nixon, 2014). Five reviews of CBIs in LMICs showed that there is potential benefit for community-based interventions to improve functional outcomes for people with disabling conditions living

within these countries (Bowers, Kuipers, & Dorsett, 2015; Cleaver & Nixon, 2014; Finkenflügel, Wolffers, & Huijsman, 2005; Iemmi et al., 2015; Yan et al., 2016), but only a few of the studies included in these reviews discussed the direct effect of CBI on the ADL performance and QOL of people with stroke. Majority of these studies on CBI are also of poor rigour and quality, thereby making the claims about the effectiveness of CBI delivered in LMICs inconclusive (Bowers et al., 2015; Iemmi et al., 2015). The lack of randomised controlled trials (RCTs) suggests the limited capacity of LMICs to conduct healthcare-oriented research (Bowers et al., 2015; Iemmi et al., 2015) possibly due to lack of interest of researchers and universities in such studies (Feng et al., 2013).The costs and training associated with conducting research and the lack of funding could have fuelled this lack of interest, or there might be some other independent reason (Bettger et al., 2019; Bowers et al., 2015; Pandian, Liu, Gandhi, & Lindley, 2017). This necessitates serious attention because CBI is provided as a rehabilitation service within the CBR framework, and the number of people with stroke who will need rehabilitation is expected to increase (Feigin et al., 2017; Magwood et al., 2020).

In addition, there is no study that has summarised the impact of CBIs applicable for LMICs on ADL performance and QOL of persons living with stroke, despite the steady growth of research concerning the effect of CBI among functional outcomes of stroke survivors within HICs (Graven et al., 2011; Magwood et al., 2020).

Objective

The growing need for effective and accessible approaches to improve the function of people living with stroke is an important issue that affects both HICs and LMICs (Bernhardt et al., 2020; WHO & World Bank, 2011), despite their differing healthcare service capacity and socio-political environments. The current systematic review was undertaken to identify CBIs for people living with stroke in HICs that are accessible in LMICs and LMICs as well, and then compare their effectiveness with usual care offered through multidisciplinary stroke units in improving ADL and QOL outcomes of stroke survivors.

METHOD

Data Sources and Searches

The Preferred Reporting Items for Systematic Reviews and Meta-analyses

(PRISMA) statement was used as a guide in the research process (Liberati et al., 2009; Moher, Liberati, Tetzlaff, & Altman, 2010). A Health Sciences librarian helped develop the search strategy. The following databases were used for the search: PubMed, Science Direct, Cumulative Index to Nursing and Allied Health Literature (CINAHL), and Scopus. The search terms used a combination of the following words: "community-based", "stroke" (or CVA), "routine" ("usual", or "hospital"), "activities" (or ADL), and "quality of life" (see Figure 1) depending on the search protocol of the databases. Search was conducted from October 18, 2018, to December 31, 2020. Push notifications were included to alert the researcher to new articles that matched the criteria.

Figure 1. Search terms used in PubMed.

#1: (stroke OR CVA OR cerebrovascular)
#2: (cbr OR "community based" OR "community-based" OR community)
#3: ((hospital based OR hospital-based) OR typical OR conventional OR standard OR usual)
#4: ((qol OR quality of life) OR (adl OR (activity OR activities)))
#5: (Randomized Controlled Trial [pt] OR Pragmatic Clinical Trial [pt] OR Controlled Clinical Trial [pt] OR Clinical Trial [pt] OR Clinical Study [pt] OR trial [tw] OR study [tw])
#6: (#2 AND #3)
#7: (#6 AND #1)
#8: (#7 AND #4)
#9: (#8 AND #5)
#10: ((Community Medicine [mh] OR Therapeutic Community [mh] OR Community Integration [mh] OR Community Health Services [mh] OR Community Networks [mh] OR Hospitals, Community [mh]))
#11: Stroke Rehabilitation [mh] OR ((Stroke [mh] OR stroke [ti] OR CVA [ti] OR cerebrovascular [ti] OR cerebrovascular [tw] OR stroke [tw]) AND rehabilitation)
#12: (Quality of Life [mh] OR qol [tw] OR "quality of life" [tw]) OR (Activities of Daily Living [mh] OR adl [tw] OR activity of daily living [tw] OR activities of daily living [tw] OR (activities OR activity))
#13: (Rehabilitation Centers [mh] OR Rehabilitation Research [mh] OR Stroke Rehabilitation [mh] OR Rehabilitation [mh] OR Hospitals [mh] OR (typical OR conventional OR standard OR usual))
#14: (#10 AND #13)
#15: (#14 AND #11)
#16: (#15 AND #12)
#17: (#8 AND #16)

The search criteria were as follows:

(1) Mention of "community-based" or "community rehabilitation" (or similar terms) in either the title, abstract or key words;

(2) Experimental studies or systematic reviews involving people with stroke and using usual or hospital care as comparison; and,

(3) The outcomes assessed in the study must include ADL (BADL or basic activities of daily living, IADL or instrumental activities of daily living, or combined) and/ or QOL.

Studies that were excluded were:

(1) Non-intervention studies and articles in languages other than English;

(2) All studies whose title and full text described CBI that focuses on advanced and/ or expensive technology that is not commonly available in LMICs (e.g., robots, virtual reality requiring specialised equipment, and treadmill with body weight support),

(3) Studies that were not completely performed within the community, or requiring clinical or hospital facilities; and,

(4) Articles published prior to 1979.

All trials comparing any intervention that is described as "community-based" for physical rehabilitation with usual or routine care and including people with stroke as participants, were included in this study.

"Community-based" was defined as either the house of the participants or facilities that are already present within their community (e.g., gyms, community or town halls, recreation centres). "Intervention" in this study included any management focusing on health, education, or social aspects of people living with stroke, that attempts to improve their functional outcomes. This may include rehabilitation, exercise, counselling, training programmes and other approaches that can be delivered to one person at a time or to a group. In addition, the term "routine" and its synonyms "standard", "conventional" and "usual", and "hospital" were used for the comparison group, to ensure that all conventional modes of rehabilitation service delivery were included in this study.

The outcomes of interest included ADL performance and QOL scores. "Basic activities of daily living" (BADL) refer to the performance of tasks related to

self-care, such as hygiene, eating, dressing, toileting and transfers (Costa Filho, Mambrini, Malta, Lima-Costa, & Peixoto, 2018; Spector & Fleishman, 1998). "Instrumental activities of daily living" (IADL) are those that must be performed to be able to stay within the community, such as shopping, transportation, gardening, housework and community ambulation (Oort et al., 2019). "Quality of life" (QOL) was defined as an individual's personal appraisal of one's place in life, in culture and in the value system where one lives and where one makes relationships to objectives, standards or interests (Beslerová & Dzuričková, 2014).

Study Selection

Duplicate copies and articles in foreign languages were removed during the title and abstract screening. The screening of the remaining articles was systematically performed by the authors to identify those that satisfied the inclusion criteria. The reference list of all the included articles was also examined for additional articles. All the articles that met the set criteria were assessed for quality using the Physiotherapy Evidence Database (PEDro) and the modified Downs and Black scale (mDBs) (Hooper, Jutai, Strong, & Russell-Minda, 2008). Only those that received a rating of fair or higher (score of 15 or higher) in mDBS were considered for the synthesis of results.

Data Extraction Process

The authors summarised and synthesised the data into a Microsoft Excel® spreadsheet using the appraisal tool developed from the Cochrane Handbook (Higgins & Green, 2011). The following information was collected: study design, country of study, baseline characteristics of the participants, details of intervention and control groups, duration of follow-up, and outcome results. The economic status of the country of study was determined as "high-income" or "low- to middle-income" based on the World Economic Situation and Prospects (WESP) 2019 criteria (United Nations, 2019). The groups were then described using the intervention they received. The community-based intervention received by the experimental group was further categorised based on the type of intervention provided (health, education, social intervention). When described in the selected studies, the facilitators and decision-makers in treatment, extent of collaboration and participation among stakeholders were also included, to allow for a clearer description of these interventions. Exercise interventions were further identified using the Frequency, Intensity, Time and Type (FITT) equation. The duration of

follow-up assessment was described in weeks or months.

The summary measures of interest for data synthesis were the pre-test and post-test values of both groups on all outcome results for ADL performance and QOL, including mean or mean change and standard deviations. Whenever appropriate, the authors of the selected articles were contacted via e-mail, to request missing information.

Risk of Bias Assessment

The selected articles were subjected to risk of bias assessment using the Physiotherapy Evidence Database (PEDro) and the modified Downs and Black rating. The PEDro scale is a widely used and valid 11-item risk of bias assessment tool for assessing RCTs (Elkins, Herbert, Moseley, Sherrington, & Maher, 2010; Macedo et al., 2010). A PEDro score for each article was either obtained from pedro.org.au or generated by the authors. The modified Downs and Black rating is a valid and reliable 27-item checklist used for a more comprehensive assessment of both randomised and non-randomised trials (Downs & Black, 1998). One of the authors (RT) and an independent reviewer separately scored each article using the mDBS criteria and discussed the results. Any unresolved inconsistencies were then sent to a research expert for arbitration. The use of both PEDro and modified Downs and Black checklists ensured fair estimation of bias for the selected articles. Assigning the level of evidence for all included studies is a necessary step in systematic reviews, as weighing the results of conflicting studies through their methodological quality ensures objectivity of drawn conclusions and allows decision-makers to be aware of the individual study's potential limitations (Centre for Evidence-based Medicine, 2016; Cotoi, Teasell, & EBRSR Research Group, 2018).

Data Synthesis and Analysis

Two healthcare statisticians assisted in the analysis of the quantitative data for this study. Estimates of mean and standard deviations were obtained based on statistical tools provided by Cochrane Handbook version 5.1.0 (Higgins & Green, 2011) and Hozo, Djulbegovic and Hozo (2005). Studies receiving a PEDro score of 6 or more are considered as "good quality" (Hahne, Ford, & McMeeken, 2010). For modified Downs and Black, a score of at least 20 was considered as "good", 15 to 19 as "fair", and at most 14 as "poor" (Hooper et al., 2008). Level of evidence was assigned for each study using the Centre for Evidence-Based Medicine

(CEBM) criteria for studies concerning treatment (CEBM, 2016), based on the type and quality of study and the confidence interval of the results. The highest level that could be obtained was '1a', and downgrading was done if the article failed to meet any of the criteria mentioned above. Meta-analysis was considered for outcomes when there were at least 3 studies using the same outcome measure (Cheung & Vijayakumar, 2016).

RESULTS

Study Selection

Of the 344 articles reviewed, 10 articles were included in this study. Title and abstract review removed 263 articles, and full text review removed an additional 13 articles (see Figure 2).

Figure 2. PRISMA flow diagram.
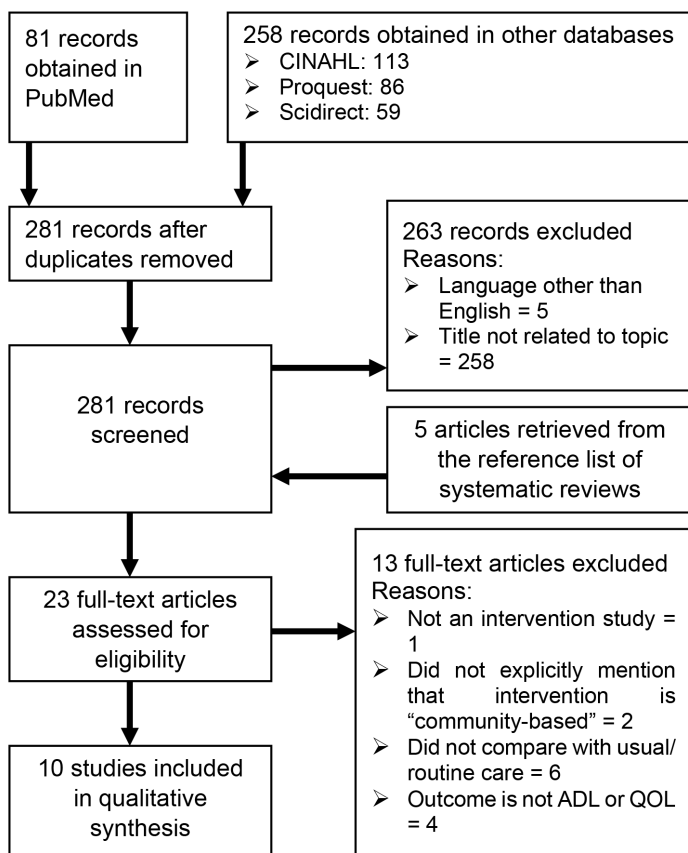
Description of Included Studies

Tables 1 and 2 below contain a summary of the details of included studies. All of the studies were published from 1997 to 2014 (17 years) and involved a total of 1,575 participants (806 males, 656 females, 113 not classified). Six were RCTs, while the rest were quasi-experimental. Five studies were graded '1b' and five studies were graded '2b' using the CEBM criteria. Also, all 10 studies came from high-income countries (Italy, United Kingdom, Canada, Australia, and South Korea). Participants were reported to be similar at baseline across all these studies; however, only age was reported consistently. Other baseline characteristics were not consistently reported, such as gender distribution (9 out of 10) and time elapsed since stroke diagnosis (5 out of 10 studies).

Table 1. Summary characteristics of studies included.

Author and Year	Country of Study	Sample Size	Duration of Study	Outcome Measures Used	Selection Criteria	Baseline Characteristics
Benvenuti et al (2014)	Italy	188	3 months	➤ **ADL:** NEADL, BI ➤ **QOL:** SIS	Inclusion: ➤ Duration post-stroke: ≥ 3 months ➤ Age: ≥ 40 y/o ➤ Paretic limb function: ≥ 3 Enjalbert Scale ➤ Permission from primary care giver Exclusion: ➤ Cognitive dysfunction ➤ Symptomatic congestive heart failure ➤ Unstable angina ➤ Under oxygen therapy ➤ Recent MI or hospitalization ➤ Pain interfering with exercise ➤ Poorly controlled BP	Age: 45 – 93* Sex: 102 Male, 86 Female Time Elapsed Since Stroke (y): 2.1 – 5.2*
Donnelly et al (2004)	United Kingdom	113	12 months	➤ **ADL:** NEADL, BI ➤ **QOL:** EQ5D, SF36, QOL	➤ Duration post-stroke: 4 weeks ➤ Potential to benefit from further rehabilitation ➤ Not a resident in a nursing or residential home ➤ No pre-existing physical or mental disability that makes further rehabilitation inappropriate	Age: 59 – 91* Sex: not indicated Time Elapsed Since Stroke (y): not indicated
Harrington et al (2010)	United Kingdom	243	12 months (ADL) 9 weeks (QOL)	➤ **ADL:** RMI, FAI ➤ **QOL:** WHOQOL-BREF	Inclusion: ➤ Age: >50 y/o at onset of stroke ➤ Returned to community > 3 months ➤ Able to participate in group activities Exclusion: ➤ Living in nursing homes	Age: 50 – 92* Sex: 132 Male, 111 Female Time Elapsed Since Stroke (y): not indicated

Jeong & Kim (2007)	South Korea	33	8 weeks	➢ **ADL:** None ➢ **QOL:** K-SSQOL	➢ Duration post-stroke: ≥ 6 months ➢ Muscle strength test: 2–4 (poor to moderate) ➢ Disability on one side of the body ➢ No history of rehabilitation ➢ Intact auditory function ➢ Ability to communicate	Age: 44 – 76* Sex: 23 Male, 10 Female Time Elapsed Since Stroke (y): 0.9 – 10*
Lincoln et al (2003)	United Kingdom	421	6 months	➢ **ADL:** NEADL, mBI ➢ **QOL:** EQ5D	Inclusion: ➢ Duration post-stroke: < 2 years ➢ Age: > 16 years ➢ Needs intervention from more than one rehabilitation discipline Exclusion: ➢ Lived outside the geographical area of the study or had been treated by the community stroke team in the previous two years	Age: 22 – 101 Sex: 222 (Male), 199 (Female) Time Elapsed Since Stroke: not indicated
Markle-Reid et al (2011)	Canada	101 (baseline)	12 months	➢ ADL: None ➢ QOL: SIS, SF-36	➢ Duration post-stroke: ≤ 18 months ➢ Newly referred to (< 2 weeks) and eligible for home care services ➢ Living in the community ➢ Mentally competent to give informed consent (or with substitute decision-maker) ➢ Competent in English (or with an interpreter available)	Age: 42 – 101* Sex: 45 (Male), 37 (Female) Time Elapsed Since Stroke: ≤ 6 months (57 out of 82)
Patterson et al (2010)	Australia	43	3 months	➢ **ADL:** None ➢ **QOL:** EQ5D	Inclusion: ➢ Community dwellers with a confirmed diagnosis of stroke Exclusion: ➢ Unable to answer the questionnaires due to cognitive/language deficit	Age: 44 – 89* Sex: 25 (Male), 18 (Female) Time Elapsed Since Stroke: 1.2 – 9*
Rudd et al (1997)	United Kingdom	331	12 months	➢ **ADL:** RADL ➢ **QOL:** NHP	Inclusion: ➢ Able to perform functional independent transfer (if alone) ➢ Able to perform transfer with assistance (if with a willing caregiver) Exclusion: ➢ Living too far away	Age: 27 – 103 Sex: 185 (Male), 146 (Female) Time Elapsed Since Stroke: not indicated
Stuart et al (2009)	Italy	93 (baseline)	6 months	➢ **ADL:** BI ➢ **QOL:** SIS	➢ Age: ≥ 40 y/o ➢ Duration post-stroke: > 9 months ➢ Function: ability to walk independently for 6 minutes at a velocity ≥30 - 90 cm/s, either with or without an assistive device ➢ No comorbid conditions that are contraindications to exercise participation	Age: 49 – 91* Sex: 54 (Male), 24 (Female) Time Elapsed Since Stroke (y): 0 – 9*
Wolfe et al (2000)	United Kingdom	43	12 months	➢ **ADL:** mBI ➢ **QOL:** NHP	➢ All patients who remained at home after stroke onset	Age: 48 – 96* Sex: 18 (Male), 25 (Female) Time Elapsed Since Stroke: not indicated

* - estimated based on 2SD (age), 1SD (stroke duration)

Table 2. Summary of risk of bias assessment.

Author and Year	Type of Study	Level of Evidence (CEBM)	Risk of Bias Assessment	Statistical Analysis Employed
Benvenuti et al (2014)	Quasi-experimental	2b	➢ **Downs and Black:** 17 ➢ **PEDro Score:** 2	➢ Per protocol
Donnelly et al (2004)	RCT	1b-	➢ **Downs and Black:** 18 ➢ **PEDro Score:** 6*	➢ Per protocol
Harrington et al (2010)	RCT	1b-	➢ **Downs and Black:** 21 ➢ **PEDro Score:** 8*	➢ Intention-to-treat
Jeong & Kim (2007)	RCT	1b-	➢ **Downs and Black:** 19 ➢ **PEDro Score:** 5*	➢ Per protocol
Lincoln et al (2003)	Quasi-experimental	2b	➢ **Downs and Black:** 19 ➢ **PEDro Score:** 4*	➢ Per protocol
Markle-Reid et al (2011)	RCT	1b-	➢ **Downs and Black:** 20 ➢ **PEDro Score:** 6*	➢ Per protocol
Patterson et al (2010)	Quasi-experimental	2b	➢ **Downs and Black:** 17 ➢ **PEDro Score:** 5	➢ Intention-to-treat
Rudd et al (1997)	RCT	1b-	➢ **Downs and Black:** 21 ➢ **PEDro Score:** 7*	➢ Per protocol
Stuart et al (2009)	Quasi-experimental	2b	➢ **Downs and Black:** 16 ➢ **PEDro Score:** 3	➢ Per protocol
Wolfe et al (2000)	RCT	1b-	➢ **Downs and Black:** 21 ➢ **PEDro Score:** 7*	➢ Intention-to-treat

* - pre-appraised in PEDro website (https://pedro.org.au/)

Various interventions were utilised in each group across the included studies; these are summarised in Table 3. For the CBI group, 5 studies used coordinated professional rehabilitation services from at least a physical therapist (PT), occupational therapist (OT), and speech language therapist (SLT). Rehabilitation services were delivered by either a multidisciplinary team that holds regular meetings to coordinate their services (Donnelly, Power, Russell, & Fullerton, 2004; Lincoln, Walker, Dixon, & Knights, 2004; Rudd, Wolfe, Tilling, & Beech, 1997; Wolfe, Tilling, & Rudd, 2000) or an interdisciplinary team that develops an integrated and individualised plan of care (Markle-Reid et al., 2011). Two studies used exercise classes facilitated by local exercise instructors supported by a physiotherapist (Harrington et al., 2009; Stuart et al., 2009), two studies used exercise combined with peer support (Patterson, Ross-Edwards, & Gill, 2010) or music (Jeong & Kim, 2007), and one study used telerehabilitation (Benvenuti et al., 2014).

Table 3. Details of intervention and results of key outcome measures assessed.

Study and Year	Details	ADL	QOL
Benvenuti et al 2014	*Intervention Group* ➢ 3 sessions therapist, 2 sessions Habilis program (adjusted depending on patient assessment) ➢ Decision-maker: Health professional ➢ Focus (CBR Matrix): Health ➢ Sample size: 143 *Control Group* ➢ Outpatient or no management ➢ Sample size: 45	*Pretest* ➢ NEADL Usual: 14 (SD: 5.37); NEADL Community: 13.2 (SD: 5.98) ➢ BI Usual: 87.4 (SD: 12.07); BI Community: 85.1 (SD: 15.55) *Posttest* ➢ NEADL Usual: 13.7 (2.01); NEADL Community: 17.31 (3.59) ➢ BI Usual: 86.9 (3.35); BI Community: 89.5 (9.57) *Significant difference?* ➢ NEADL: Yes ➢ BI: Yes	*Pretest* ➢ Not reported *Posttest* ➢ SIS Communication Usual: 0.3 (SD: 4.02); SIS Communication Community: 2.6 (SD: 10.76) ➢ SIS ADLs Usual: 0.2 (SD: 6.04); SIS ADLs Community: 5.7 (SD: 26.31) ➢ SIS Mobility Usual: -0.8 (SD: 7.38); SIS Mobility Community: 5.6 (SD: 23.92) ➢ SIS Manual Dexterity Usual: -1.1 (SD: 6.71); SIS Manual Dexterity Community: 7.3 (SD: 13.15) ➢ SIS Participation Usual: 2.2 (SD: 12.07); SIS Participation Community: 3.0 (SD: 11.96) *Significant difference?* ➢ SIS Communication: No ➢ SIS ADLs: Yes ➢ SIS Mobility: Yes ➢ SIS Manual Dexterity: Yes ➢ SIS Participation: No

Donnelly et al 2004	**Intervention Group** - Home visit x 45 minutes x 2.5/week, multidisciplinary meetings involving patient and closest relative - Decision-maker: Health professionals - Focus (CBR Matrix): Health - Sample size: 59 **Control Group** - Hospital-based - Sample size: 54	*Pretest* - NEADL Hospital: 5.77 (4.79); NEADL Community: 4.95 (5.39) - BI Hospital: 13.89 (3.93); BI Community: 14.14 (3.38) *Posttest* - NEADL Hospital: 10.43 (5.92); NEADL Community: 12 (6.34) - BI Hospital: 17.15 (3.81); BI Community: 17.98 (3.10) *Significant difference?* - NEADL: No - BI: No	*Pretest* - EQ5D Hospital: 59.17 (16.15); EQ5D Community: 60.48 (18) - SF-36 Physical Functioning Hospital: 35.35 (7.2); SF-36 Physical Functioning Community: 35.04 (7.72) - QOL Hospital: 16.53 (3.65) - QOL Community: 17.67 (4.14) *Posttest* - EQ5D Hospital: 68.21 (20.31); EQ5D Community: 66.36 (18.45) - SF-36 Physical Functioning Hospital: 34.67 (32.01) - SF-36 Physical Functioning Community: 35.59 (31.32) - QOL Hospital: 18.92 (4.74); QOL Community: 18.57 (4.29) *Significant difference?* - EQ5D: No - SF-36 Physical Functioning: No - QOL: No
Harrington et al 2010	**Intervention Group** - Group exercise: 1-hour circuit training for balance, endurance, strength, flexibility, function and well-being) and interactive education in leisure and community centers x 2/week - Decision-makers: Local exercise instructors supported by PT - Focus (CBR Matrix): Health - Sample size: 119 **Control Group** - Referral information about usual services - Sample size: 124	*Pretest* - BI Control: 19 (2.22); BI Community: 18 (3.70) - FAI Control: 20 (11.22); FAI Community: 15.5 (16.49) - RMI Control: 12 (11.36); RMI Community: 11 (8.24) *Posttest* - BI: not reported - FAI Control: 21 (8.28); FAI Community: 17 (15.76) - RMI Control: 12 (8.31); RMI Community: 12 (5.23) *Significant difference?* - FAI: No - RMI: No	*Pretest* - WHOQol-Bref Physical Control: 53.6 (19.20) - WHOQol-Bref Physical CBR: 53.6 (28.3) - WHOQol-Bref Social Control: 66.7 (35.84) - WHOQol-Bref Social CBR: 58.3 (36.5) *Posttest* - WHOQol-Bref Physical Control: 53.6 (22.26) - WHOQol-Bref Physical CBR: 57.1 (56.20) - WHOQol-Bref Social Control: 66.7 (34.08) - WHOQol-Bref Social CBR: 66.7 (26.79) *Significant difference?* - EQ5D: No - SF-36 Physical Functioning: No - QOL: No

Jeong and Kim 2007	*Intervention Group* ➢ RAS music-movement (repetitive, rhythmic movements) x 2/ week ➢ Decision-makers: Health professionals ➢ Focus (CBR Matrix): Health ➢ Sample size: 16 *Control Group* ➢ Referral information about usual services ➢ Sample size: 17	None	*Pretest* ➢ K-SSQOL Control: 2.54 (0.80); K-SSQOL Community: 3.25 (1.08) *Posttest* ➢ K-SSQOL Control: 2.92 (0.90); K-SSQOL Community: 3.58 (0.87) *Significant difference?* ➢ K-SSQOL: No
Lincoln et al 2003	*Intervention Group* ➢ Treatment delivered by multidisciplinary team of PT, OT, SLP, Mental health nurse, and Rehabilitation support worker ➢ Decision-makers: Health professionals ➢ Focus (CBR Matrix): Health ➢ Sample size: 189 *Control Group* ➢ Outpatient or hospital-based ➢ Sample size: 232	*Pretest* ➢ not reported *Posttest* ➢ BI Routine: 16 (5.19); BI Community: 16 (4.44) ➢ NEADL Routine: 25.5 (20.74); NEADL Community: 24 (18.52) *Significant difference?* ➢ BI: No ➢ NEADL: No	*Pretest* ➢ Not reported *Posttest* ➢ EQ5D Routine: 55 (23.70); EQ5D Community: 52 (27.41) *Significant difference?* ➢ EQ5D: No

| Markle-Reid et al 2011 | *Intervention Group*

➢ Regular home visits, screening, risk factor modification, education, caregiver support, referral and linkage to health and social services, monthly case conferencing, and evidence-based community reintegration plan by interprofessional team of care coordinator, nurse, PT, OT, SLP, dietitian, social worker, personal support worker
➢ Decision-makers: Health professionals
➢ Focus (CBR Matrix): Health
➢ Sample size: 52

Control Group

➢ Routine follow-up, referral information and private care
➢ Sample size: 49 | None | *Pretest*

➢ SIS-16 Usual: 60.86 (21.59); SIS-16 Community: 54.58 (25.71)
➢ SF-36 Physical Function Usual: 32.82 (25.20); SF-36 Physical Function Community: 26.94 (27.23)
➢ SF-36 Role-Physical Usual: 36.46 (28.18); SF-36 Role-Physical Community: 28.39 (30.58)
➢ SF-36 Social Functioning Usual: 56.41 (32.43); SF-36 Social Functioning Community: 54.65 (35.78)

Posttest

➢ SIS-16 Usual: 60.36 (22.94); SIS-16 Community: 52.74 (30.59)
➢ SF-36 Physical Function Usual: 28.85 (28.48); SF-36 Physical Function Community: 28.84 (30.68)
➢ SF-36 Role-Physical Usual: 50.33 (28.21); SF-36 Role-Physical Community: 47.14 (35.22)
➢ SF-36 Social Functioning Usual: 59.29 (30.71); SF-36 Social Functioning Community: 66.57 (34.69)

Significant difference?

➢ SIS -16: No
➢ SF-36 Physical Function: No
➢ SF-36 Role-Physical: No
➢ SF-36 Social Functioning: No |
| Patterson et al 2010 | *Intervention Group*

➢ Exercise training and peer support (sharing accounts of personal experience and adjustments to daily life) supervised by OT and PT x weekly
➢ Decision-makers: Health professionals
➢ Focus (CBR Matrix): Health
➢ Sample size: 22

Control Group
➢ Class (Group discussion)
➢ Sample size: 21 | None | ➢ EQ5D: F[1,36]-0.032

Significant difference?

➢ EQ5D: No |

Rudd et al 1997	*Intervention Group* ➢ Domiciliary care added to conventional care x maximum one daily visit from each therapist; facilitated by team of PT, OT, SP ➢ Decision-makers: Health professionals ➢ Focus (CBR Matrix): Health ➢ Sample size: 167 *Control Group* ➢ Stroke unit, medical/ elderly care ward, outpatient: hospital or domiciliary, usual community resources ➢ Sample size: 164	*Pretest* ➢ BI Conventional: 15 (4); BI Community: 15 (4) ➢ Rivermead ADL: not reported *Posttest* ➢ BI Conventional: 16 (4); BI Community: 16 (4) ➢ Rivermead ADL Conventional: 27 (11); Rivermead ADL Community: 27 (12) *Significant difference?* ➢ BI: No ➢ RADL: No	*Pretest* ➢ NHP Conventional: 10 (7); NHP Community: 11 (7) *Posttest* ➢ NHP Conventional: 12 (8); NHP Community: 14 (9) *Significant difference?* ➢ NHP: No
Stuart et al 2009	*Intervention Group* ➢ 1-hour APA-stroke exercise class x 3/ week x gymnasium and home ➢ Decision-makers: Health professionals ➢ Focus (CBR Matrix): Health ➢ Sample size: 49 *Control Group* ➢ Medical care ➢ Sample size: 44	*Pretest* ➢ BI Control: 85.4 (SD: 13.27); BI Community: 79.5 (SD: 18.2) *Posttest* ➢ BI Control: 86.1 (SD: 6.63); BI Community: 83.4 (SD: 11.9) *Significant difference?* ➢ BI: No	*Pretest* ➢ SIS communication Control: 88.3 (SD: 19.24); SIS communication Community: 74.6 (SD: 28.7) ➢ SIS mobility Control: 80.7 (SD: 21.23); SIS mobility Community: 68.9 (SD: 18.2) ➢ SIS participation Control: 61.5 (SD: 28.52); SIS participation Community: 59.4 (SD: 23.1) *Posttest* ➢ SIS communication Control: 89.5 (SD: 13.27); SIS communication Community: 81.8 (SD: 21) ➢ SIS mobility Control: 78.3 (SD: 13.93); SIS mobility Community: 75.7 (SD: 17.5) ➢ SIS participation Control: 52.3 (SD: 21.23); SIS participation Community: 71 (SD: 23.1) *Significant difference?* ➢ SIS Communication: No ➢ SIS Mobility: No ➢ SIS Participation: Yes

	Intervention Group	Pretest	Pretest
Wolfe et al 2000	➢ Maximum of one daily visit by each therapist with consultant coordinating team of PT, OT, SLP, and therapy aide ➢ Decision-makers: Health professionals ➢ Focus (CBR Matrix): Health ➢ Sample size: 23 *Control Group* ➢ Hospital or domiciliary outpatient care, usual community resources ➢ Sample size: 20	➢ BI usual: 15.5 (SD: 3); BI rehabilitation: 15.25 (SD: 3.25)/ Posttest ➢ BI usual: 19 (SD: 1); BI rehabilitation: 16 (SD: 3) *Significant difference?* ➢ BI: No	➢ NHP usual: 12.75 (SD: 7.25); NHP rehabilitation: 13 (SD: 7); Posttest ➢ NHP usual: 12.5 (SD: 6.5); NHP rehabilitation: 9.5 (SD: 7) *Significant difference?* ➢ NHP: No

The comparison group also received different interventions. In 6 studies, medical care or rehabilitation in the hospital or clinics was utilised (Benvenuti et al., 2014; Donnelly et al., 2004; Lincoln et al., 2004; Rudd et al., 1997; Stuart et al., 2009; Wolfe et al., 2000). Two studies utilised the service of care coordinators who managed the overall rehabilitation care of participants, besides providing them with information sheets (Harrington et al., 2009; Markle-Reid et al., 2011). These coordinators determined the eligibility of people with stroke for professional and non-professional services, prior to arranging and coordinating with the providers (Markle-Reid et al., 2011). One study used peer support services conducted at a local community hall (Patterson et al., 2010) and another study used referral services about the usual care available in their community (Jeong & Kim, 2007).

There are also differences on the temporal aspects of the included articles. Time elapsed since stroke diagnosis ranged from less than 6 months to approximately 10 years. Regarding the follow-up testing, one study conducted follow-up after 2 months (Jeong & Kim, 2007), one study after 9 weeks (Harrington et al., 2009), two studies after 3 months (Benvenuti et al., 2014; Patterson et al., 2010), two studies after 6 months (Lincoln et al., 2004; Stuart et al., 2009), and five studies after 12 months (Donnelly et al., 2004; Harrington et al., 2009; Markle-Reid et al., 2011; Rudd et al., 1997; Wolfe et al., 2000).

Review of the modified Downs and Black checklist scores showed that 6 studies

received "fair" rating (Benvenuti et al., 2014; Donnelly et al., 2004; Jeong & Kim, 2007; Lincoln et al., 2004; Patterson et al., 2010; Stuart et al., 2009) and 4 studies received "good" rating (Harrington et al., 2009; Markle-Reid et al., 2011; Rudd et al., 1997; Wolfe et al., 2000). Analysis of the items further revealed that many of the included studies have issues with the reporting of principal confounders (Donnelly et al., 2004; Harrington et al., 2009; Lincoln et al., 2004; Markle-Reid et al., 2011; Patterson, 2010; Rudd et al., 1997), presence of adverse effects (Donnelly et al., 2004; Harrington et al., 2009; Jeong & Kim, 2007; Lincoln et al., 2004; Markle-Reid et al., 2011; Patterson, 2010; Wolfe et al., 2000), and comparison of baseline characteristics of consenters and non-consenters (Donnelly et al., 2004; Harrington et al., 2009; Jeong & Kim, 2007; Lincoln et al., 2004; Markle-Reid et al., 2011; Patterson, 2010; Rudd et al., 1997; Stuart et al., 2009; Wolfe et al., 2000). Studies that used multidisciplinary approaches were also unable to clearly report the intervention. These 4 studies (Donnelly et al., 2004; Lincoln et al., 2004; Rudd et al., 1997; Wolfe et al., 2000) have unclear descriptions of the community-based interventions delivered to the recipients. The studies only reported the average amount of time per session during which the participants had received rehabilitation services from occupational therapists, physical therapists, speech-language therapists and nurses. However, the type and intensity of treatment delivered by these professionals were not identified.

Control of bias was also inadequate as there are issues with blinding of participants (Benvenuti et al., 2014; Donnelly et al., 2004; Harrington et al., 2009; Jeong & Kim, 2007; Lincoln et al., 2004; Markle-Reid et al., 2011; Patterson, 2010; Rudd et al., 1997; Stuart et al., 2009; Wolfe et al., 2000). Many studies failed to use intention-to-treat analysis when needed (Benvenuti et al., 2014; Donnelly et al., 2004; Jeong & Kim, 2007; Lincoln et al., 2004; Markle-Reid et al., 2011; Patterson, 2010; Rudd et al., 1997; Stuart et al., 2009), and detect clinically important effect (Benvenuti et al., 2014; Donnelly et al., 2004; Harrington et al., 2009; Jeong & Kim, 2007; Lincoln et al., 2004; Markle-Reid et al., 2011; Patterson, 2010; Stuart et al., 2009; Wolfe et al., 2000).

The review of PEDro scores showed similar issues with allocation, blinding and outcomes assessment. Five studies received "good" rating in PEDro scale. Three out of 10 studies accounted for all participants in the follow-up assessment, with 2 studies using intention-to-treat statistical analysis and 1 study having no drop out. Meta-analysis was not performed due to insufficiency of studies that used similar outcome measures.

Outcomes related to Activities of Daily Living

Seven out of 10 studies reported six ADL outcome measures: Barthel Index (BI) and its modified version (mBI), Nottingham Extended Activities of Daily Living Scale (NEADL), Rivermead Mobility Index (RMI), Frenchay Activity Index (FAI), and Rivermead ADL scale. Either BI or RMI was used by 7 studies to measure improvement in BADLs, while NEADL or FAI was used by 3 studies to measure improvement in IADLs.

Of the 7 studies, only 1 study (Benvenuti et al., 2014) reported significantly better improvement in BADLs (p = 0.0001) and IADLs (p < 0.002) for the CBI group compared to usual care (visit to general practitioner and outpatient PT). The remaining 6 studies reported between-group comparisons that show no statistical difference for BADL or IADL outcomes (Donnelly et al., 2004; Harrington et al., 2009; Lincoln et al., 2004; Rudd et al., 1997; Stuart et al., 2009). Five out of 6 compared BADL outcomes, with one study showing higher mean value for CBI, another one favouring the control group, and the rest showing similar mean values for both groups. On the other hand, three out of 6 compared IADL outcomes: one study reported higher mean value for CBI, while the other two studies favoured the control group among the three studies that used outcome measures for IADL.

Within-group comparisons were not reported by five out of 7 studies (Benvenuti et al., 2014; Donnelly et al., 2004; Lincoln et al., 2004; Rudd et al., 1997; Wolfe et al., 2000). Two studies did not report baseline values for at least one ADL outcome measure (Rudd et al., 1997; Lincoln et al., 2004), and 4 studies did not report statistical significance of difference between pre- and post-test values of at least one ADL outcome measure (Benvenuti et al., 2014; Donnelly et al., 2004; Rudd et al., 1997; Wolfe et al., 2000). Nevertheless, all studies showed improvement of baseline mean values at follow-up for the ADL outcome measures of the CBI group. In the usual group, 1 study (Benvenuti et al., 2014) showed decreased performance for both BADLs and IADLs. The remaining 2 studies (Harrington et al., 2009; Stuart et al., 2009) reported statistically significant change between baseline and follow-up values. One study (Stuart et al., 2009) reported that there was significant improvement on BADLs for the CBI group only, while the other (Harrington et al., 2009) reported improvement on both BADLs (mobility) and IADLs for both the CBI and usual groups.

Outcomes related to Quality of Life

All 10 studies included QOL as an outcome of interest, using 8 different questionnaires, namely Stroke Impact Scale (SISv2 and SIS-16), EuroQol 5 Dimensions (EQ5D), Nottingham Health Profile (NHP), Quality of Life assessment (QOL), World Health Organisation Quality of Life -BREF (WHOQOL-BREF), Korean Stroke-Specific Quality of Life Scale (K-SSQOL), and Nottingham Health Profile (NHP). Among these 10 studies, 2 reported that CBI resulted in statistically significant better outcomes for selected areas of SISv2 (Benvenuti et al., 2014; Stuart et al., 2009) compared to usual care. Benvenuti et al. (2014) reported significant difference in QOL associated with ADLs, mobility, and manual dexterity favouring CBI, while Stuart et al. (2009) reported significantly better QOL outcomes for participation in the CBI group. The rest of the studies did not report between- group statistically significant QOL improvement.

Among the 8 studies that failed to reach statistically significant results, one study (Rudd et al., 1997) reported greater post-test values for the CBI group (CBINHP=14$\pm$9; Usual=12$\pm$8; p=0.11), while two studies (Lincoln et al., 2004; Wolfe et al., 2000) reported post-test values in favour of the control group (CBIEQ5D=52$\pm$27.41, Usual EQ5D=55$\pm$23.70, p=0.75; CBINHP=9.5$\pm$7; Usual NHP=12.5$\pm$6.5; p=0.16). Four studies reported CBI and control groups surpassing each other in different sections of the outcome measures (Donnelly et al., 2004; Harrington et al., 2009; Jeong & Kim, 2007; Markle-Reid et al., 2011). No comparison can be made for one study (Patterson, 2010) because the mean for each group was not provided.

Within group analysis was reported only in the studies of Harrington et al. (2009) and Stuart et al. (2009). In these studies, those that received CBI improved significantly in the Psychological section of the WHOQOL-BREF, and in the Communication and Participation sections of SISv2. Among the 6 studies that presented the mean values for the QOL measures in both groups, 3 studies (Benvenuti et al., 2014; Donnelly et al., 2004; Harrington et al., 2009; Jeong & Kim, 2007; Lincoln et al., 2004; Markle-Reid et al., 2011; Patterson, 2010; Rudd et al., 1997; Stuart et al., 2009; Wolfe et al., 2000) reported lack of positive change in score in at least one area of the QOL measure for CBI and 2 studies (Benvenuti et al., 2014; Markle-Reid et al., 2011) for the control group. In these studies, it was observed that there are more instances of decreased mean values for the control group than for CBI.

DISCUSSION

This systematic review revealed the current level of research about the effectiveness of community-based interventions in improving outcomes related to ADL performance and quality of life among people with stroke. The review showed the emerging trend demonstrating that CBI is at least as effective as usual care, and in some cases better, in improving both ADL performance and QOL. Even though most of the included studies failed to reach statistical significance for between-group comparison of post-test values, these studies were reporting better follow-up mean/mean change values for the CBI group, particularly in QOL (Benvenuti et al., 2014; Rudd et al., 1997; Stuart et al., 2009).

The absence of randomisation and blinding is an important confounding factor that affected generalisability of the study results (Armijo-Olivo et al., 2017; Kamper, 2018). However, it should be recognised that blinding and randomisation may be difficult to implement in community-based research. For example, blinding of treatment assignment is likely to be impossible in rehabilitation research where participants must be part of the decision-making throughout the research process (WHO & World Bank, 2011), and in trials wherein the settings in which the intervention is performed are visibly different between groups (Nichol, Bailey, & Cooper, 2010; WHO & World Bank, 2011). One of the studies included in this review even showed that political and ethical factors can preclude randomisation of participants in a community-based study (Stuart et al., 2009).

The included studies show that a wide range of CBIs focusing on health are used to improve ADL and QOL outcomes. This is an expected phenomenon, as numerous interventions can be designed as community-based to target multiple functional outcomes (Bowers et al., 2015; Graven et al., 2011; Iemmi et al., 2015; Markle-Reid et al., 2011). Approaches such as telerehabilitation, team rehabilitation, and exercise were discussed in some studies as potentially useful rehabilitation interventions for developing countries (Bettger et al., 2019; Yan et al., 2016). In addition, the focus of all interventions was clearly on the medical aspects of rehabilitation such as reduction of body impairments and activity training, in contrast to those that are more participation-oriented which involve changing of community perceptions and family relationships, or empowerment interventions which include the formation of self-help groups (Bowers et al., 2015). The focus of interventions on medical care was possibly because all the implementers are health professionals, who may have received stroke rehabilitation training limited to solving issues concerning the physical aspects of health and wellbeing. It is possible that QOL outcomes did not improve as much because of lack of

interventions that specifically targeted psychosocial factors such as depression, self-esteem issues, isolation, or economic issues. Despite this limitation, the type of intervention can influence health-related QOL outcomes, particularly in the physical and social participation domains. This can be inferred from 2 studies using different interventions (Benvenuti et al., 2014; Stuart et al., 2009) that resulted in significant QOL outcomes on dissimilar areas, in spite of having similar characteristics such as the outcome measures used, geographic location, age of participants, length of follow-up period, and the absence of randomisation and blinding.

The search strategy was unable to retrieve articles that described interventions focusing on other important areas that can improve ADL performance and QOL such as education, livelihood, and social wellbeing. One reason for this outcome is the current view about stroke rehabilitation being a health issue, so that most of the management was focused on health outcomes. This is similar to the concern raised by some interest groups about the medical nature of the term "rehabilitation" (De Groote, 2019). Additionally, the constructs "ADL" and "QOL" are closely associated and have historical ties with health and rehabilitation. Both of these concepts have been initially and widely used in the medical field (Costa Filho et al., 2018; Pennacchini, Bertolaso, Elvira, & De Marinis, 2011). While rehabilitation is undeniably an important strategy towards the improvement of ADL and QOL outcomes, IADLs and QOL have a close relationship with economic and social activities such as access to employment and support systems. This underscores the need for exploring the importance of focusing rehabilitation also on other components of the CBR Matrix, which are also linked with improved functional independence and quality of life (Mahesh et al., 2018; Wang & Langhammer, 2017; World Health Organisation & Swedish Organisations of Disabled Persons International Aid Association, 2002). Empowerment is another emerging area for research, focusing currently on health empowerment and not active social participation (Iemmi et al., 2015; Sit et al., 2016; WHO & SHIA, 2002). Another reason for the lack of returned articles may have been the limited databases used in this study which could have skewed the findings towards community-based interventions focusing on health, despite previous reviews already noting the focus of CBI on health needs of persons living with stroke (Bowers et al., 2015; Iemmi et al., 2015). The lack of freely accessible databases among LMICs is also an important contributor to insufficient infrastructures for accessing and even expanding research (WHO & World Bank, 2011), aside from the potential lack of data concerning CBI.

The current study obtained more articles specific to the research question than the previous reviews (Bowers et al., 2015; Iemmi et al., 2015). As expected, all the research articles included in the study came from high-income countries. The result exemplifies the persistent lack of high-quality community-based research output in low- and middle-income countries and any country with low resources noted in the previous years (Bowers et al., 2015; Iemmi et al., 2015).The limited number of returned articles vis-à-vis the presence of interventions that do not require intensive participation from health professionals (Harrington et al., 2009; Stuart et al., 2009) highlights the need for improving the research capacity of LMICs, and also presents an important reason for including HICs in CBI research within the context of community-based rehabilitation. This need can be further inferred based on the recent bibliometric analysis of research concerning stroke rehabilitation which shows that 75% of the published works from 2003-2013 were from HICs (Feng et al., 2013). Regardless of the country of origin, there is still an overall lack of research on the impact and parameters of specific CBIs, possibly denoting that both HICs and LMICs are not fully engaged in this field of research.

It is possible that the term "community-based intervention" has been inconsistently used up to the present, and this may have affected the search process as well. This is evidenced by how different authors from HICs and LMICs used this term, or used terms other than this, within their studies. "Community-based Rehabilitation" (CBR) was defined by the World Health Organisation (2010) as "a strategy within general community development for the rehabilitation, poverty reduction, equalisation of opportunities and social inclusion of all people with disabilities," coming from their joint position statement with the International Labour Office and United Nations Educational, Scientific and Cultural Organisation in 2004. CBR is focused on approaches that are developed in low-resource, capacity-constrained settings, especially LMICs (WHO, 2010). However, this term has been used throughout the literature to be synonymous with CBI within or outside the context of the CBR programme itself, whether it is developed within high-income countries (Bettger et al., 2019; Graven et al., 2011; Handberg, Mygind, & Johansen, 2019; Jackson, Troeung, & Martini, 2020; Jeong & Kim, 2007) or low- and middle- income countries (Iemmi et al., 2015; Yan et al., 2016).This makes searching for CBIs applicable to LMICs a tedious process.

Another example is the use of terms such as "domiciliary care" or "home-based treatment" which were noted during the search process (Olaleye, Hamzat, & Owolabi, 2013). These terms could have also referred to CBI within the context

of CBR, as the authors compared which interventions provide more accessible services. Though these articles were rejected due to difference in the outcomes of interest, future attempts to investigate CBI must consider these terms and any other terms that may also denote a similar construct. Indeed, there is a need to standardise the concept of CBR throughout the literature in order to consolidate evidence about the effectiveness of CBI particularly for persons living with stroke.

It is also worth mentioning that the heterogeneity of the selected ADL and QOL outcomes may have been influenced by the variety of interventions implemented for both CBI and usual care groups. This is particularly true in studies which used multidisciplinary services as a form of intervention for CBI, as most of these studies utilised individualised approaches which resulted in different types and intensity of interventions. To arrive at stronger conclusions however, these interventions and measures must be homogenised to allow meta-analysis of outcomes. The use of standardised rehabilitation procedures and measures and the accurate description of management must be consistently implemented in future studies to allow better estimation of outcomes (Bowers et al., 2015).

It is also possible that the selected studies reported better outcomes for usual care as the clients are already receiving high-quality traditional rehabilitation services. Those countries with better conventional rehabilitation services will report CBI as comparable to or less than the current ones. LMICs must look for alternative methods of delivering rehabilitative services such as CBI, because usual care in these places is more burdensome, costly, impractical, and/or inaccessible. Researchers from both HICs and LMICs must be cognisant that CBIs must at least be comparable to tested usual rehabilitation interventions in delivering outcomes to be considered effective.

This study reflects a major gap in CBI research on stroke rehabilitation and effectiveness of CBI on health-related outcomes. It is important for researchers and other stakeholders coming from high-income countries to partner with those in low- and middle-income countries in conducting research concerning effective and applicable CBI for stroke rehabilitation. Determination of cost-effective and accessible CBI for people with stroke is a shared issue that needs urgent response.

CONCLUSION

Community-based interventions have the potential to be effective strategies for improving the ADL and QOL outcomes of people with stroke. More studies

concerning CBIs involving different components of the CBR Matrix are needed to conclusively ascertain their effectiveness. There is also a need to standardise the terminologies to promote retrieval of evidence, and interventions and outcome measures to improve the strength of conclusions and applicability of the results of similar reviews in the future.

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Extra-Institutional Factors Limiting Access to Rehabilitation Services for Children with Cerebral Palsy: Perspectives of Caregivers in Marsabit County, Kenya

Hilary Kibele Harawo[1*], Wisdom Kwadwo Mprah[2]

1. Moyale Hospital, Kenya
2. Kwame Nkrumah University of Science and Technology, Kumasi, Ghana

ABSTRACT

Purpose: This paper explored the factors limiting access to and use of hospital-based rehabilitation services for children with cerebral palsy in Marsabit County, Kenya. The factors were unrelated to healthcare institutions providing the services and the focus was on the perspectives of caregivers of children with cerebral palsy.

Method: A qualitative study was conducted with a total of 18 participants who were selected by purposive sampling. Semi-structured interviews were used to collect data from the participants. Data was analysed using Erlingsson and Brysiewicz's approach to content analysis.

Results: The major barriers for the caregivers were belief systems, lack of awareness of rehabilitation services, no support at home, transport problems, and cost of transport.

Conclusion and Implications: Access to rehabilitation services for caregivers of children with cerebral palsy appear to be limited. Health policymakers, service providers and other stakeholders should ramp up their efforts to improve access to these services and make them services not expensive, but caregivers experience transport problems in terms of its unavailability and cost as well. Efforts at improving access could be supported by information and awareness-creation among caregivers about the importance of rehabilitation services for children with cerebral palsy.

Key words: disability, traditional healers, service users, caregivers, cerebral palsy, service providers, utilisation

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* **Corresponding Author:** Hilary Kibele Harawo, Moyale Hospital, Kenya.Email:hilaryharawo@gmail.com

INTRODUCTION

According to Article 25 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), it is a fundamental human right for all persons with disabilities to have unhindered access to healthcare and health-related rehabilitation services (UN, 2006). Thus, access to rehabilitation services for children with cerebral palsy is not only essential but is also a right and in line with the Sustainable Development Goal 3 (SDG3), which requires States to promote healthy lives and well-being for every individual (UN, 2017).

The Government of Kenya's (GoK) efforts to improve access to healthcare for children with disabilities predates the UNCRPD and the SDG3. For example, Kenya's Children Act 2001 has provisions to promote the right to health for all children. The Act states that good health is a basic right of every child and thus, children with disabilities shall be treated with dignity and without discrimination in terms of access to healthcare services. The Act mandates that persons with disabilities should be provided with free healthcare services or at a reduced cost whenever possible (Kenya Children's Act, 2001).

Furthermore, the 'Kenya Health Policy 2014–2030' recognises the need for accessible healthcare, including health-related rehabilitation, to all persons with disabilities (GoK, 2014). To ensure access to health facilities, the policy advocates for physical access to health facilities and services by 2030, defined as "living at least 5 km from a health service provider where feasible and having the ability to access the health service" (GoK , 2014).

However, access to rehabilitation services remains inadequate worldwide, especially in low- and middle-income countries (LMICs) due to many barriers (WHO, 2017). These barriers include lack of awareness of rehabilitation services among the general public (Barnes, Dolan, Gardner, Stevens & Zack, 2012), as well as inadequate and unavailable services at community level (WHO, 2017; UN, 2018). Many children with disabilities, such as those with cerebral palsy, do not often have access to healthcare services, let alone rehabilitation services. For example, it is estimated that worldwide, about 85% of children with disabilities live in LMICs and less than 5% of them have access to basic rehabilitation services (Maloni et al, 2010; WHO, 2017; Bright, Wallace & Kuper, 2018). Poor public transport has been reported to have negatively influenced access to rehabilitation services in rural areas of LMICs, such as Kenya (Ensor & Cooper, 2004; Moïsi et al, 2011). Long-distance travel to and from the health facilities is one major

reason for discontinuation of rehabilitation services by caregivers of children with disabilities (Mishra & Siddharth, 2018).

The limited access to rehabilitation services in LMICs is affected by other barriers such as cultural beliefs and financial constraints. A study in Bangladesh revealed that lack of understanding of the causes of cerebral palsy limited children's access to rehabilitation services. The study reported that most caregivers believe the condition was caused by bad spirits and, as a result, many caregivers visited traditional healers for treatment (Zuurmond, Mahmud, Polack & Evans, 2015). Due to cultural reasons, some people opt for traditional healing methods instead of formal rehabilitation services (Wegner & Rhoda, 2015). In some cases children are hidden from public view by their parents, due to stigma and shame attached to the conditions, resulting in late detection and appropriate intervention for the children (UNICEF, 2007). Additionally, the socioeconomic status of families, like occupation and level of income, has been reported to be the major barrier to access rehabilitation services, even in higher-income countries such as the USA (O'Neil, Costigan, Gracely & Wells, 2009).

The situation is not different in Kenya. A study by Bunning et al (2014) in Kenya reported transportation problems and inadequate social support for caregivers as challenges to access rehabilitation services. According to the study, poor staffing in rural areas had compelled many parents to travel long distances to seek services in urban areas, coping with the added difficulty of poor transportation from rural to urban areas. Similarly, a study on the rehabilitation of children with cerebral palsy in Nairobi, Kenya, cited not only a high incidence of cases of cerebral palsy but also revealed barriers in utilising rehabilitation services, such as high costs of services (Ngota, 2018). This situation is likely to be worse in remote areas such as Marsabit County because most rehabilitation professionals prefer to render services in urban areas (UN, 2018).

The current study explored extra-institutional barriers limiting caregivers' access to and use of rehabilitation services. The focus is on external factors that did not emanate from the rehabilitation centres.

Objective

Accessible rehabilitation services are essential for children with cerebral palsy in order to improve their functioning, increase independence and quality of life. This study explored the extra-institutional barriers limiting service utilisation that are experienced by caregivers of these children.

METHOD

Study Setting

The study was undertaken at the Marsabit County Referral Hospital (MCRH) and Moyale Sub-County Referral Hospital (MSCRH), both in Marsabit County, Kenya. Marsabit County shares borders with Turkana County on the West, Wajir County to the East, Isiolo and Samburu County to the South and Ethiopia to the North. Marsabit County is approximately 70,961.2 square kilometres in terms of land area (Ministry of Health-Kenya, 2018) and Marsabit and Moyale are its two major towns.

The two referral hospitals are the only health facilities where rehabilitation services for children with cerebral palsy are offered in the region. These hospitals receive referral cases from across the County, as far as Illeret, located 550 kilometres away from Marsabit town (Ministry of Health- Kenya, 2018). MSCRH also treats children with cerebral palsy from the Ethiopian side of the County.

Study Sample

The targeted population was caregivers whose children were diagnosed with cerebral palsy and who were seeking rehabilitation services at MCRH and MSCRH. Purposive sampling was used to select 18 participants for the study - 11 from MSCRH and the rest from MCRH. Emmel (2013) asserted that purposive sampling allows researchers to select cases of rich information that will provide insights into the subject matter. The selection of caregivers was done with the help of service providers, who reviewed the departments' registers of clients to identify those who met the inclusion criteria.

Caregivers who had used services from the selected hospitals for at least one year were considered to have enough experience to be able to contribute to the study. Only caregivers who were able to communicate either in English or Kiswahili were chosen.

The researchers explained the purpose of the study to all the participants individually and those who agreed to participate signed a consent form.

Data Collection

A qualitative data collection method was used. The focus was on gathering data that would provide in-depth insights into factors that are not created

by institutions providing services but affect access to and the utilisation of rehabilitation services. The perspectives of the caregivers were of interest.

Semi-structured interviews were conducted in private rooms in each hospital, to ensure participants' confidentiality. The interviews helped the study participants to express their views on what influenced their access to rehabilitation services and allowed the interviewers to probe for in-depth information on the topic. Cohen and Crabtree (2006) observed that interviews allow interviewees the freedom to express their views freely on the subject and can provide reliable and comparable qualitative data.

All the interviews were recorded on audiotapes with consent from the participants, and observations made during the interviews were written down in a field diary.

Data Analysis

The data obtained from the interviews was analysed using Erlingsson and Brysiewicz's (2017) approach to content analysis: condensation, coding, categorisation and forming themes.

The process of analysis started with a transcription of the audio-recordings in Word format. Transcription was done by an independent person, fluent in both Swahili and English. The researchers then read the transcripts and compared them with the audiotapes to ensure accuracy. They subsequently re-read all the transcripts carefully, noting significant points (meaning units) made by the participants on the left margins of the transcripts. These were then condensed and assigned codes. Related codes were grouped to form categories. Based on the underlying meanings, similar categories were merged to form themes. The themes were listed and clustered according to the objective of the study. Some verbatim expressions from study participants were quoted to support the themes. To ensure anonymity of participants and maintain confidentiality of the information obtained, the cryptograms MBT P1-P7 (for caregivers from MCRH) and MYL P1-P11 (for caregivers from MSCRH) were used while citing the verbatim extracts from transcripts.

Ethical Considerations

Approval for the study was obtained from each Hospital as well as from the Department of Health Promotion and Disability Studies of Kwame Nkrumah University of Science and Technology (KNUST) in Ghana. Ethical approval was

received from the KNUST Committee of Human Research Publications and Ethics, where the study protocol was reviewed and cleared before study implementation. All those who agreed to participate in the study signed a consent form.

RESULTS

Demographic Features of Caregivers

Of the 18 caregivers interviewed, 77.8% were females. The majority of the caregivers (83.3%) were Muslims, and more than three-quarters (77.8%) were below the age of 28 years. Also, more than three-quarters (83.3%) of the children were below three years of age, except for three of them who were between four and six years old (see Table 1).

Table 1: Demographic Features of Caregivers

Variables	Category	Frequency (n=18)	Percentage (%)
Gender	Male Female **Total**	4 14 **18**	22.2 77.8 100
Age of Caregivers (yrs)	18-28 29-38 39-48 49-58 **Total**	14 1 2 1 **18**	77.8 5.6 11.0 5.6 **100**
Age of Child (yrs)	<1Yr 1-2 3-4 5-6 **Total**	8 7 1 2 **18**	44.4 39 5.6 11.0 **100**
Education Level	Primary Secondary Tertiary None **Total**	5 6 3 4 **18**	27.8 33.3 16.7 22.2 **100**
Occupation	Employed Self-employed None Unknown **Total**	2 6 9 1 **18**	11.1 33.3 50 5.6 **100**

Marital Status	Married	16	89.0
	Unknown	2	11.0
	Total	**18**	100
Religion	Christian	3	16.7
	Muslim	15	83.3
	Total	**18**	**100**
Relationship with the Child	Mother	12	66.7
	Father	4	22.2
	Relative	2	11.1
	Total	**18**	**100**
Affiliated Hospital	MYL Hospital	11	61.1
	MBT Hospital	7	38.9
	Total	**18**	**100**

Factors Influencing Access to Rehabilitation Services

The factors influencing access to rehabilitation services for children with cerebral palsy are presented under the following sub-headings: physical distance; cost of transportation; support from family members; parenting role expectations; lack of knowledge of cerebral palsy and rehabilitation services; and belief in religious and traditional healers.

Physical Distance

Living far away from the facilities was a challenge for the caregivers. Many participants wished they had services closer to them, because distance made it difficult to access services for their children.

"If I get a place that is near, I will be very happy because I just take the child to the nearest place" (MYL P11).

This assertion was supported by another caregiver.

"If therapy doctors can come home, it is going to be good for us because there are parents who cannot even come here (hospital) *because of the distance..."* (MYL P1).

The number of visits to the hospitals was reduced for some caregivers because of distance.

"…they told me, since I am coming from far, they can see me once in a week… because transport is also a problem…" (MBT P7).

Cost of Transportation

An important factor also related to distance is cost of transportation. Many caregivers said that since they could not afford the transport cost to the health facilities, they sometimes had to walk there, and it was very tedious.

"When I have money, I come on a motorbike because it is faster. Many times, I come on foot because I didn't have money" (MYL P1).

"I stay far from here. I always come on foot. I do not have cash for transport because it's expensive" (MBT P5).

Some of the caregivers complained that they experienced health problems such as back pains because of carrying their children and wished they had enough money to travel by vehicles.

"If I have money, I could have come by car, because now there are times you have back pain because of carrying him…." (MBT P5).

Consequently, some caregivers stopped going to services when their children grew older because it was difficult to carry them to the facilities.

"…she (child) *is too heavy for me to bring her all the time here* (hospital)*"* (MYL P2).

Support from Family Members

Social support from family members played an important role in service utilisation among the participants. Caregivers who had support at home seemed more likely to use rehabilitation services while facing fewer challenges than those without support.

"At home I have support. The child's grandmother, my husband's mother, stays with us… she helps me a lot with the child… I don't have any problem at home hindering me from coming here (hospital)*"* (MYL P1).

Caregivers who received a lot of support from their respective husbands said something similar.

"The child's father is also very supportive of the treatment…he always comes with me when he has time" (MBT P7).

"His (child's) *father cooperates well, and he does not want the child to miss treatment here* (hospital)*"* (MYL P8).

However, those without support lamented that they were unable to visit the hospital regularly.

> *"I was alone, and no one was helping me to bring the child…I couldn't bring him to the hospital regularly"* (MYL P9).

> *"The days I go and fetch water, I do not come* (hospital). *It's very tiresome and I cannot make it to come here* (hospital) *again… you cannot get water immediately and I do not have someone to help me bring him to the hospital. It's only me"* (MBT P5).

Parenting Role Expectations

The roles expected of each gender influenced the use of rehabilitation services among the participants. According to some of them, although their spouses were supportive, the mothers were responsible for going with their children to the hospital and this was regarded as a big challenge.

> *"But you know men about children… they are not so conversant and not responsible for that. So, l have to commit to bringing my child for treatment. He* (the father) *is so cooperative with treatment…, but now he can't carry that small child here* (hospital). *That one is my responsibility"* (MYL P10).

> *"Besides that, there was no other person who can take the child to hospital apart from me. Her father is very busy. I also do not expect him to assist me with that… that is my duty"* (MBT P3).

Lack of Knowledge of Cerebral Palsy and Rehabilitation Services

The findings indicated that some caregivers did not have sufficient information about the existence of rehabilitation services. In consequence, they did not utilise the services until they were informed about them.

> *"The child was not feeling well. I came to the hospital to see the children's doctor. I told him everything and the child's neck is not strong; then he sends me here* (physiotherapy). *I did not know of places to do children's exercises before he sends me here* (physiotherapy)*"* (MYL P8).

> *"There is a lady who told us that if a child cannot sit, walk or has a problem like my child, there is a place to treat in the hospital. She said her sister used to take her child to Moyale hospital and after receiving exercises, her child can sit alone.*

She told us to take the child to a hospital and see how she can be assisted instead of only taking to traditional healers" (MYL P2).

"One day the child was sick, with fever, coughing…and we came here (hospital) *to see the doctor. After checking the child, he gave us drugs and told us to take him to physiotherapy"* (MYL P5).

It also emerged that many caregivers did not know about the usefulness of rehabilitation services for children with cerebral palsy, and this possibly delayed the use of the services.

"At first, for me, rehabilitation is a place for taking people with mental problems. I did not know it's a place where you can even take children with CP too" (MBT P3).

Lack of knowledge of cerebral palsy had influenced the utilisation of rehabilitation services. Some caregivers said they did not even know anything about cerebral palsy and wished that they did.

"I did not know a child can develop problems at birth. If I knew the problem, we could have started treatment for a long time. But the problem was that I did not know" (MBT P2).

Belief in Religious and Traditional Healers

The existing beliefs in the healing power of religious and traditional healers also affected the use of rehabilitation services. The interviews showed that misconceptions about the causes of cerebral palsy and the necessary interventions have led many caregivers to seek assistance from religious and traditional healers.

*"The reason why I did not come early to the hospital is because of many things they are telling me at home…some even told me that I am cursed and thus I need to see the witchdoctor" (*MBT P2).

"When people see your child like this, they tell you to read the Quran, and his father, following the pressure from people, went to bring a Sheikh home" (MYL P8).

"We have taken him to the Sheik to read him Quran for three months and there was no improvement, but now after bringing my child here (hospital) *I see there are changes; he can even sit alone"* (MYL P5).

There seemed to be so much trust in religious and traditional healers among some caregivers that they started rehabilitation on the advice of these healers.

> *"One of them* (healers) *told me that this child's problem is on the legs, just go and see the physiotherapist...that is when I came here* (hospital)*"* (MYL P7) .

> *"…even the traditional healer told us not to stop the hospital exercises"* (MYL P5).

DISCUSSION

This study explored the barriers that caregivers of children with cerebral palsy face in accessing rehabilitation services. The focus was on barriers that did not emanate from the rehabilitation centres, but rather on the external obstacles limiting caregivers from accessing available rehabilitation services provided by health institutions.

The study's findings indicated that misconceptions about the causes of disability were one of the major factors that influenced the use of rehabilitation by the caregivers. The perception in the study area is that disability, including cerebral palsy, is a curse or evil. This has caused caregivers to believe that exorcism and interventions by traditional healers could cast out the evil spirit. This belief system has contributed to underutilisation of services among caregivers of children with cerebral palsy. The finding is in line with the findings of other studies done in Bangladesh and South Africa, for instance, in which cultural beliefs about disability have been identified as an obstacle for accessing rehabilitation services (Zuurmond et al, 2015; Wegner & Rhoda, 2015). In these studies, traditional beliefs about the causes of disability were a major barrier as people thought that their condition was spiritual and could not be remedied by biomedical interventions such as rehabilitation.

However, findings from the current study suggest that traditional and religious leaders could play an important role in the rehabilitation process of children with cerebral palsy. Caregivers in this area trust these healers so much that some of them started using rehabilitation services based on their advice. Thus, some of the traditional and religious leaders served as 'referral' points for the rehabilitation centres. Traditional healers (and religious leaders) do not always prevent people from accessing biomedical interventions such as rehabilitation services. This is a lesson to service providers and therefore they need to be aware of and sensitive to cultural beliefs of the local population. Rehabilitation service providers need

to be knowledgeable about the influence of traditional and religious leaders and invest in collaboration with these people, informing and training them about the importance of rehabilitation services so that they can incorporate the positives of the tradition into their practices.

The study's findings that children with cerebral palsy make less use of rehabilitation services as they get older, is consistent with some studies done elsewhere. For example, in a study that examined the experiences of parents of children with cerebral palsy on accessing therapy services in the US, O'Neil et al (2009) reported that as children aged, their chances of using rehabilitation services decreased. The findings of the current study indicate that children above 3 years of age rarely attend rehabilitation services because they become heavier as they grow older, and caregivers find it difficult to carry them to rehabilitation centres, which is further complicated by lack of transport and long distances people must travel to and from the health facilities (Bunning et al, 2014). Moïsi et al (2011) identified transportation as a major factor that influences access to the rehabilitation services. According to the authors, the underutilisation of services by poor families, especially those in rural areas of LMICs such as Kenya, Burkina Faso, Congo and Tanzania was due to poor public transportation. Similarly, Ensor and Cooper (2004) were of the view that attempts to address accessibility issues often lay too much emphasis on skills of staff, treatment protocols, availability of supplies, and health facilities, at the expense of transport and cost, which is viewed as pivotal to service accessibility and utilisation. In the current study, inadequate and unaffordable transport services limited access to services for the caregivers of children with cerebral palsy. This is made worse by poverty and lack of support from family members. This indicates that the Government of Kenya's policy which addresses the importance of making healthcare accessible to all by improving physical access to health facilities, is still a challenge as far as rehabilitative services are concerned (GoK, 2014).

The findings also point to a lack of understanding of the importance of rehabilitation services among some participants. This is not surprising, as previous studies have reported similar findings. According to Wegner and Rhoda (2015) and Barnes et al (2012), the importance of rehabilitation service is often overlooked and undervalued among parents due to lack of awareness about the value of such services. Wegner and Rhoda (2015) discovered that ignorance about disability and the usefulness of rehabilitation services were reasons for caregivers to opt for traditional healers. This may result, in some cases, in children

with disabilities being hidden in homes and could result in too late detection, interventions and underreporting on the condition (UNICEF, 2007). This could contribute to invisibility of this group of children for national policymaking on disability and rehabilitation issues, and hence stop them from benefitting from the necessary rehabilitation interventions.

Implications

The findings of this study have implications for service providers, health policymakers and other stakeholders involved in the provision of rehabilitative services in the County. The findings highlight the need to bring services closer to the communities through outreach and community-based rehabilitation programmes to ensure that those who need them, get them. Although there are some challenges associated with the above approaches, such as inadequate (trained) staff and lack of resources, it is evident that district hospitals and rehabilitation centres by no means offer the solution to the rehabilitation needs of people living in remote and rural areas. If well-planned with community leaders, it will be very helpful in the early detection and referral of cases to the appropriate specialists in the hospitals. For example, outreach programmes could be carried out on specific days, for specific communities. Minor cases which do not require regular medical attention could also be handled during the outreach visits, thus reducing the frequency of travel to health facilities by caregivers.

Measures, such as awareness-creation and education about disability issues and the importance of rehabilitation for children with cerebral palsy, can increase the timely use of rehabilitation services among caregivers. Health promotion and education can also address traditional and cultural beliefs about the causes of disabilities, to reduce misconceptions and increase access to rehabilitation services. For example, promotion of partnership with traditional healers and religious leaders by the rehabilitation service providers will allow the inclusion of positive aspects of traditional practices into the rehabilitation process and consequently improve access to services for the caregivers of children with cerebral palsy.

CONCLUSION

This study explored extra-institutional factors that limit the use of rehabilitation services among caregivers of children with cerebral palsy in Marsabit County. The findings are alerting stakeholders, such as policymakers and rehabilitation

service providers, to the barriers limiting utilisation of rehabilitative services in the region and pointing to the need to adequately respond to those challenges. The study findings are a call to service providers and other stakeholders working with persons with disabilities, to be aware of and understand the local context in order to adapt their services to the specific needs of their clients.

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CBR Practice and Inclusion: Persons with Disabilities in Northeast India

Nandini Ghosh*

ABSTRACT

Purpose: *This paper explores the long-term impact of CBR programmes implemented in the Northeast region of India. The aim was to understand the ways in which targeted interventions led to changes in the lives of persons with disabilities and their families, to discern the extent of their inclusion within communities and any systemic changes brought about towards accessing their human rights.*

Method: *Data was collected from three CBR programmes for persons with disabilities in Northeast India, 3 years after financial support to the programmes had stopped. Persons with disabilities were selected through stratified random sampling. In-depth interviews were conducted and the primary data was analysed in the light of the baseline and endline surveys/reports, reports of DPOs, and implementing agencies.*

Results: *As a result of CBR initiatives and their sustainability after conclusion of the structured programmes, persons with disabilities, their families and communities experienced a change in the quality of their everyday lives and had better access to a range of rights and entitlements. Persons with disabilities also have improved status within their families and communities, enjoy better quality of relationships, play an active role in family and community decision-making, and gain dignity and respect.*

Conclusion and Implications: *The CBR programmes brought visible changes in the lives of persons with disabilities in terms of self-sufficiency, independence, inclusion in education and within the community, as well as securing livelihoods. Those who benefited the most from the CBR programmes were persons with mild to moderate disabilities, while people with severe disabilities were pushed to the periphery, especially after cessation of the programmes. There is a need for continuous upgrading of skills and information/ knowledge among families,*

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* **Corresponding Author:** Assistant Professor of Sociology, Institute of Development Studies, Kolkata, India. Email:nandinighosh@gmail.com

DPOs and communities so that advocacy for entitlements, rights and systemic changes is constant.

Key words: *CBR programmes, Northeast India, inclusion, sustainability*

INTRODUCTION

In low- and middle-income countries (LMICs), Community-based Rehabilitation (CBR) was advocated as a core strategy in the 1970s-80s for improvement in the quality of life of persons with disabilities by providing them facilities for rehabilitation at the community level. CBR developed from within a medical model perspective, implemented in the context of the health sector to deliver primary rehabilitation services to persons with disabilities in their communities (Nilsson & Nilsson, 2002). The current practice of CBR, based on the social model and human rights, includes medical interventions, rehabilitation strategies, advocacy for equal opportunities and basic rights, as well as building linkages and networks leading to empowerment. Although the western social model of disability advocates for a shift from service delivery (only) to the human rights models of CBR, in low- and middle-countries CBR often is a community development programme which is multidisciplinary and addresses all areas that are central for the improvement of quality of life of persons with disabilities. It is seen as a strategy to promote the rights of persons with disabilities to enjoy health and well-being and to participate fully in educational, social, cultural, religious, economic and political activities. CBR is implemented through the combined efforts of persons with disabilities themselves, their families and communities, and the appropriate health, education, vocational and social services (ILO, UNESCO &WHO, 2004). CBR emphasises that persons with disabilities should be active partners in the planning and implementation of all measures affecting their civil, political, economic, social and cultural rights. Though limited in scope and coverage, CBR works well in smaller communities where the majority of persons with disabilities do not have any access to any form of rehabilitation (Velema et al, 2008). Most CBR developments are more bottom-up grassroots initiatives managed by non-governmental organisations (NGOs), rather than by governments (Corneilje, 2009).

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, 2007) and the CBR Matrix (WHO, 2010) in the CBR Guidelines (WHO, UNESCO, ILO & IDDC, 2010) touch upon different key aspects of life including

education, health, work and employment, social protection and participation (Deepak et al, 2014). The CBR Guidelines launched in 2010 promotes CBR as a comprehensive strategy for implementing the Convention on the Rights of Persons with Disabilities (Yuenwah, 2012). Mannan et al (2012) use the CBR Guidelines and CBR Matrix to highlight that CBR needs to engage with rehabilitation along with issues such as advocacy, community mobilisation, self-help, livelihood, and social dimensions. CBR activities are designed to improve the quality of life and meet the basic needs of people with disabilities, reduce poverty, and enable access to health, education, livelihood and social opportunities – all these activities support the aims of the UNCRPD (IDDC, 2012). The social and rights-based approaches focus on change within communities and society to become more inclusive, with increased attention to equal opportunity and full participation. CBR is complex as an approach and strategy; it has many dimensions, layers, contexts and aspects. As CBR involves many layers (from the medical to the social), it uses multiple strategies and different ways of responding, and involves many contexts and stakeholders (Jones, 2011). The components of the CBR Matrix, namely health, education, livelihood and social inclusion, relate to key development sectors, while the fifth component, empowerment, is fundamental to ensuring access to the development sectors, and to the rights and quality of life of persons with disabilities (Yuenwah, 2012). In LMICs, issues of poverty, hunger and inequalities, and emerging challenges from, for instance, urbanisation to the economic developments or its lack of development, shape CBR programmes addressing the needs of persons with disabilities, their families and communities in which they live (Bongo et al, 2018).

Evidence from multiple and diverse sources, and the use of a variety of methods, are required to understand the effects of CBR. The collection of evidence has to be collaborative in nature, with a focus on participatory knowledge generation, with pertinent involvement of people with disabilities, their families and communities. While there have been many studies on the efficacy of CBR in India, many of these are not available in the public domain. However, there are studies that have demonstrated the way in which CBR has effected attitudinal change at community level and increased participation of persons with disabilities in communities. Chatterjee et al (2003) demonstrated how the CBR approach has been effective in reducing the extent of disability and building acceptance within community in rural central India. Deepak et al (2014) demonstrated that CBR programmes in India did have a positive impact across all the five domains

of the CBR Matrix. However, the impact on communities and the changes in lives of persons with disabilities varied by type of disability and social location: different groups of persons with disabilities benefited differently from different activities. Persons with physical disabilities seemed to benefit from CBR in more areas compared to persons with other types of disabilities (Deepak et al, 2014). Mijnarends et al (2011) identified conditions needed for a sustainable CBR programme, which included the availability of human resources, training, monitoring and evaluation, collaboration, commitment and financing. While human resources and awareness of disability are always poor in the contexts of LMICs, evaluation of CBR programmes suggest that persons with disabilities are more satisfied with comprehensive programmes than with those that only provide medical interventions.

With poor access to health, education, rehabilitation services and livelihoods, persons with disabilities in India have low status within their families and communities. This prevents their participation and inclusion in larger social processes. In Northeast India, persons with disabilities and their families are further disadvantaged by the geographical terrain, the climatic conditions and the resultant lack of services.

Objective

CBR programmes usually keep persons with disabilities and the community as their twin foci. This paper explores the long-term impact of CBR programmes undertaken in the Northeast region of India, in to order understand the ways in which targeted interventions led to positive changes in the lives of persons with disabilities and their families. It also aimed to discern the extent of their inclusion within communities and any systemic changes brought about towards accessing their human rights.

METHOD

Study Setting

CBR has usually been initiated in regions which are remote and underserved in terms of services for persons with disabilities. It is often implemented in rural areas with the purpose of empowering persons with disabilities and facilitating the creation of a favourable environment for their effective participation and

inclusion in the community. The CBR programmes evaluated for the current research were located in the largely mountainous states of Assam, Mizoram and Nagaland in Northeast India.

Guwahati, Aizawl and Dimapur were the three field contexts in Assam, Mizoram and Nagaland respectively. All three areas, whether the rural outskirts of Guwahati, urban Aizawl or semi-urban Dimapur, have steep hilly slopes and are vulnerable to floods and landslides. The summers are hot and humid, followed by torrential monsoons and severe winters. Roads are poor and public transport is very limited,with few buses, autorickshaws, and shared taxis. The population in Aizawl and Dimapur comprises mainly tribal Christians, while in Guwahati it includes Scheduled Castes/Scheduled Tribes and other groups. Many of these people are landless and are engaged in rural occupations like agriculture, collection of forest produce, fish culture, livestock rearing, and traditional trades like bamboo craft, weaving, pottery,as well as casual labour or earning daily wages in different sectors. They have little access to social amenities.

Study Design

Three community-based rehabilitation (CBR) programmes mentored by Caritas India CBR (CI CBR) and supported by Light for the World were part of this evaluation study conducted during 2018-2019.The main point of assessment was to understand the extent and ways in which the interventions undertaken during the pendency of a CBR programme impacted the lives of persons with disabilities within families and communities, as well as to find out how far the initiatives have sustained, three years after the completion of the programme. On one hand the study mapped the extent to which CBR interventions led to inclusion and effective participation of persons with disabilities in education, livelihoods and social activities within communities. On the other hand, it attempted to understand the knowledge and skills built up within communities with regard to the identification of persons with disabilities, referral for services and entitlements, and caring for those with severe disabilities. The evaluation also analysed the situation of the Disabled People's Organisations (DPOs) developed during the period of the CBR project, in order to understand the nature of their operations, their sustainability and self-sufficiency.

Study Sample

The three CBR programmes were mentored and supported for a period of 9 years

by CI CBR and Light for the World. CI CBR works primarily in rural areas, and in 2020 it had 62 NGO partners implementing 77 programmes across 20 states and 1 Union Territory of India, reaching out to about 83, 785 persons with disabilities. CI CBR facilitates CBR in rural areas primarily through building capacities, first at the level of the NGO and its staff to implement the CBR programme, and then through the transfer of knowledge and skills to persons with disabilities and their families and to members of the community to enable the development of more inclusive communities. Light for the World, an international disability and development organisation which works with people with disabilities in some of the poorest regions of the world,supported all the three projects throughout the whole period of project implementation. The three programmes selected for evaluation had all started their CBR interventions around 2007-08 and had been active in the selected communities till the years 2016-17.

Data Collection

Multiple methods, primarily qualitative, were used to gain an understanding of the present situation of persons with disabilities and their families within the communities where they are located. To get an idea of the achievements and the status at the time the programmes were terminated, archival analysis was done of reports generated during the final years of the three programmes. Baseline and end line surveys/reports, reports of DPOs, implementing agencies and CI CBR were consulted. Primary field-based data was collected in 2 phases for each programme, with one resource person visiting the field area at the initial stage of the evaluation, followed by a second resource person to ensure coverage of all categories of persons with disabilities, along with interactions with a wide range of government and other functionaries. The study area included 76 villages across 4 blocks of 3 districts in the 3 states. The total number of persons with disabilities identified in the three programmes can be seen in Table 1.

Table 1: Type of People with Disabilities

Sl. No.	Type of Disability	Total		
		M	F	Total
1	Blindness	13	11	24
2	Low Vision	45	26	71
3	Leprosy Cured	1	1	2
4	Hearing Impairment	129	86	215

5	Locomotor Disability	182	98	280
6	Mental Illness	16	21	37
7	Intellectual Disability	82	47	129
8	Autism	2	0	2
9	Cerebral Palsy	34	18	52
10	Multiple Disabilities	20	16	36
11	Others	5	4	9
Total:		529	328	**857**

It was decided to sample 10% of the population for the evaluation study, i.e., 86-90 people, primarily persons with disabilities and their family members, as well as community members like school teachers, representatives of the local administration, church officials, health workers etc., across the three CBR projects. Data was collected from a total of 64 persons with disabilities, with 32 men and 32 women (see Table 2). The persons with disabilities in this study were selected using proportionate stratified random sampling, after stratifying the entire population with disability by different disability categories, then selecting proportionate samples from each category to ensure all groups were represented. Care was taken to ensure representation by gender and ethnic group. The evaluation study thus covered 29 villages out of 76 villages from the selected CBR programmes.

Table 2: Sample of Interviewed People with Disabilities

Type of Disability	Total
Locomotor Disability	22
Cerebral Palsy	14
Hearing Impairment	7
Intellectual Disability	13
Low Vision	3
Psycho-social Disability	3
Multiple Disability	2
Total	**64**

Data was also collected from 27 family members in these areas, primarily representing children with disabilities and 23 members of 12 DPOs. Additional data was collected from 20 key informants in the community which included village headmen, village council members, schoolteachers, integrated child development workers, health workers and other influential members of the

community, members of other Community Based Organisations and government officials.

Data was collected using semi-structured questionnaires, through interviews and focus group discussions.

Data Analysis

As the data is primarily qualitative, evidence collected through field-based study was compared with the existing quantitative and qualitative data documented during the final phase of the programmes, and analysed to elaborate the changes that took place within communities which contributed to inclusion of persons with disabilities in different areas of their lives. The major thrust of the analysis was to ascertain the extent to which the interventions that were started during the implementation of the CBR programmes had endured after the withdrawal of the structured interventions, and the ways in which the lives of persons with disabilities and their families had changed, leading to enhanced participation, dignity, and inclusion within communities. Hence the analysis followed the case study method, where the three programmes were seen as cases, and all the persons met for the evaluation were informants to build the case. The data collected has been analysed at case level and across cases, revealing interesting details about contexts, CBR programmes and their implementation and long-term implications.

Ethical Considerations

Ethical principles have been followed in the reporting of the data, whereby all names have been anonymised.

RESULTS

In all the three areas, persons with disabilities were regarded as a burden by their families and communities. In the primarily tribal Christian communities of Dimapur and Aizawl they were well cared for within families, but in Guwahati there was a sense of neglect, especially in poor families. There were very few services or service providers available in the area for persons with disabilities. Families, who were able to seek some sort of care, had to take their children with disabilities to urban centres, which was both time-consuming and expensive, and hence untenable in the long run as disability interventions require prolonged

periods of involvement. There was little knowledge and few skills available to manage and address rehabilitation needs of people with different impairments. Ideas of incapacity and dependence kept persons with disabilities confined to homes and excluded them from education, livelihood and social participation. The limited knowledge and skills to manage and address rehabilitation needs, resulted in limited physical and mental development of persons with disabilities; subsequently this was used to justify exclusion from education and livelihoods. Given the inhospitable hilly terrain, and the poverty and lack of available services, persons with disabilities were isolated from society at large. There was very little awareness about their rights and little knowledge about how to claim entitlements.

The Effects of the CBR Programme

The lack of knowledge and services in these areas meant that there were very few people available who were trained in disability work. As Kuipers and Cornielje (2012) have pointed out, CBR programmes can become sustainable if they contribute towards improving the quality of life of persons with disabilities. One of the major aspects of sustainability is the availability of human resources, which means skilled and trained personnel who can offer meaningful interventions to persons with disabilities, families and communities, while at the same time building the capacity of people in the community. Across the 3 sites, long-term support in the form of intensive training and mentoring to the implementing agencies, contributed to changes at the grassroots level. The strategy was to train teams on disability work and CBR strategies - from identification to planning and implementing of interventions, along with field-based support and training - by people vastly experienced in 'doing' CBR in the following years. As a CBR worker from Aizawl reported,

> *"We learnt so many things during the training, from identifying persons with disabilities to mobilising groups and communities to advocacy with the administration."*

Another CBR worker from Dimapur stated,

> *"The field-based training gave us confidence as we could actually see how the activities were to be implemented at the ground level."*

The hand-holding support by experienced people in the field of disability helped in identification of persons with disability, planning and implementation

of area-specific interventions, support at home and in schools, training in life skills and preparing for livelihoods, and organising persons with disabilities into groups. Another facilitating factor for programme sustainability in CBR is the organisational setting, coordination and programme management (Jacobset al, 2007; Gruen et al, 2008). The partner organisations implementing the CBR programmes had strong connections and acceptance within the community, and good networking with the state administration and other service providers; this had a strong impact on the effectiveness of the CBR programmes. While one was a church-based organisation (in Aizawl), the others had strong roots in the selected communities through their work with disadvantaged groups.

At the end of the programme period of 9 years, there was evidence of changes that had taken place at the individual, family and community levels, through the interventions at home and linkages with the service providers as well as provision for inclusion into larger systems and processes. CBR programmes were able to successfully link persons with disabilities to health, education and administrative systems. These enabled access to schools, the provision of aids and appliances, medicines, treatment and therapy, all of which contributed to improved quality of life and led to increased participation within communities. As knowledge and skills of family and community members increased, there was enhanced awareness on disability, health and rehabilitation concerns, and improved access to rights and entitlements. With families realising the potential of their relatives with disabilities and investing in terms of time, effort and other resources, there was vast improvement in the skill sets and capabilities of persons with disabilities. Livelihood support to families through the DPOs led to activities such as piggery, pickle making, tailoring, weaving, starting petty shops, etc., which in turn contributed to families and communities valuing and respecting persons with disabilities. CBR programmes also resulted in local systemic changes through sensitisation of the different government departments, like education, transport, social welfare, and health. As a result, persons with disabilities were better linked to social security entitlements and other social schemes, and classrooms and health services became inclusive. Community-level advocacy has resulted in the inclusion of persons with disabilities in cultural, recreational, social and religious life of the community, like church events, Sunday school, youth and children's groups. As people in the community realised that persons with disabilities could be included in different ways in everyday life activities, stigma has reduced within communities and measures to facilitate participation,such as creating barrier-free environments, have been implemented

in places like schools and banks.

In keeping with the CBR Matrix, these programmes promoted the formation of DPOs at the village level which were federated at the block level. The DPOs, trained on rights and advocacy strategies as part of the CBR interventions, established networks among themselves and together developed relationships with the block and district-level officials. Many of the DPO members participated in community meetings, meetings of the *Gram Sabha* (the primary body of the Panchayati Raj system where discussion takes place on local governance and need-based plans for the village), cultural programmes, sports, competitions, plays, etc. Some of them also contested local body elections. The block-level DPOs lobbied with the block-level administration to resolve issues of persons with disabilities and collaborate with various networks and other alliances and groups at district, state and national level. For example, effective advocacy by the Nagaland State Disability Federation led to the revival of the District Disability Rehabilitation Centre in Dimapur, which provides aids and appliances for persons with disabilities.

Long-term Impact: Lessons for Sustainability

The impact evaluation, done two years after the CBR project and direct support to communities had ended, reveals that contextual realities combined with systemic changes influence the extent of inclusion of persons with disabilities within families and communities. In a context where there was little knowledge about disability and development, where the geographical terrain and weather conditions are adverse, where there were few support services for persons with disabilities, the CBR programmes have been able to entrench within communities an entire range of knowledge and skills around disability identification, referral and interventions, provision of services and promoting inclusion within communities.

Inclusion into Communities

The major impact of the programme has been in terms of changing attitudes towards persons with disabilities. The CBR and later DPO interventions have ensured that most communities and their leaders and service providers are aware of disability and persons with disabilities. In Aizawl and Dimapur, which are Christian dominated communities, the major advocacy had been with the churches and church groups like Sunday-school teachers, youth groups, and

women's groups. Advocacy with these groups ensured inclusion not only in church activities but also in the community, as church groups are drawn from community members themselves and have proved to be influential in changing attitudes.

> *"We did not think persons with disabilities could do anything. During the programme we learnt about including them and we are continuing it. This year we have taken a decision to make all churches under our parish accessible"* (Parish priest in Mizoram).

People now believe that persons with disabilities also can be capable of doing many things, and there is enhanced acceptance of disability. However there is still more work to be done in terms of changing community attitudes and ensuring that persons with disabilities have equal status as citizens. Improved inclusion is demonstrated in the increased participation of persons with disabilities in community activities, an increasing trend of marriages of persons with disabilities, and persons with disabilities being candidates in local elections.

Knowledge of identification and referral by community people, and support for accessing disability identity cards and associated entitlements, are being taken up actively by church leaders, teachers, families and persons with disabilities themselves, as well as ASHA workers (Accredited Social Health Activists or trained female community health workers) who are envisaged to be the first port of call for any health- related demands of deprived sections of the population, especially women and children, who find it difficult to access health services.

> *"We are now easily able to identify children with disabilities in our area. We learnt to screen, identify and refer at risk children during the CBR interventions"* (Anganwadi worker).

The relationships built within the community at village level, with the village council members, service providers, families and neighbours of the persons with disability, have helped in sustaining the efforts initiated during the CBR programmes. One of the major outcomes is the presence of a group of committed people, both staff of the project and persons with disabilities who have emerged as leaders during the project period.

> *"Now the church leaders and Village Council members always take into account persons with disabilities while planning development and other activities"*(Young woman with locomotor disability, Dimapur).

"As we are also in the same community, families of persons with disabilities and even village leaders come to us or call us if they have any specific problem. We share the necessary information or link them up with services"(CBR coordinator, Guwahati).

Family members of persons with disabilities and DPO leaders became resource persons within the community, linking other persons with disabilities to support services and entitlements, both within and outside the project area. Many of these entitlements include access to proper housing and toilets, which make life easier and more comfortable.

"When I went to the Village Council, the headman asked me to talk to a family with a child with disability in another village. They wanted information on what to do. I have spoken to them many times and helped to get a disability certificate also"(DPO leader, Aizawl).

"Through continuous advocacy, we have managed to get a 'pucca' house built under the Panchayat housing scheme, which helps the people with severe disabilities to move around easily within the home" (Female DPO leader, Guwahati).

"With the help of a women's group, our DPO has ensured that a girl with disability in our village got an accessible toilet constructed within the house. Now she not only has access to proper hygiene but is also safe as she does not have to go out for using the toilet." (Female DPO leader, Dimapur)

Within communities, as discrimination has become less and awareness around issues faced by persons with disabilities has increased, people help families of persons with disabilities seeking medical care and other services to access different schemes and programmes. Although the CBR work was difficult in terms of limited financial resources, working with communities and convincing families, the long-term impact is sustainable in terms of people in the community taking responsibility and connecting with CBR staff and the implementing organisations on a regular basis. Larger developments that came out of the CBR programmes were the Parents' Associations, setting up of District Disability Rehabilitation Centres (DDRCs), State-level Disability Federations and a sports organisation called 'Special Olympic Bharat'.

Inclusion of Persons with Disabilities in Different Spheres of Life

The CBR programmes provided a stimulus for the individual physical, mental and educational development of persons with disabilities by building their capacity and that of their family members. The knowledge and skills of parents and families that developed to improve the quality of life of persons with disabilities, has remained as an asset within the community. Families and persons with disabilities themselves realised the utility of such interventions in terms of, for instance, developing independent living skills, access to education and livelihoods, improved family and personal lives. The strategies for physical, mental, educational and social development transferred to families have been used to improve daily living skills, promote independence of persons with disability and enhance their quality of life. This has become an important resource on which the families depend since the withdrawal of the project.

"During the programme we were taught different ways of stimulating our daughter, who has cerebral palsy, for mobility, functional activities like eating, dressing and also for speech. We continued the same, and she has kept improving"(Mother of a girl with disabilities, Guwahati).

"We had learnt to make a low cart for her mobility using local resources. I have made a new one for him when the previous one broke down"(Father of a boy with disabilities, Dimapur).

"The school has been very encouraging. Whenever required, I can go and share my concerns and they try to respond. The teachers often tell me to communicate with my son, when they find it difficult"(Mother of a boy with hearing impairment, Aizawl).

Some of the Mothers' Groups are at present providing support to one another to the extent possible with their limited skills, along with helping families with newly identified children with disabilities to navigate fears around the uncertain development of their children. Families that have members with disabilities are supporting one another and DPOs are connecting families to enable exchange of ideas and skills.

People with epilepsy and mental illness also have been continuing to take medicines and counselling services available free of cost at the Government Hospital. The availability of such essential medication has ensured that these people can participate better in the activities within their homes and in the community.

"I know where to get the medicines but if I have problems in going to the hospital, the community people support me. Either someone accompanies me, or they get the medicines for me" (Person with mental illness, Guwahati).

The impact of the CBR programmes is clearly visible in the increased participation by children and young adults with disabilities in schools, church-based and Children's Groups and other community activities. The CBR programmes have engendered social and community-level inclusion, with friendships being forged with peers without disability on whom they can rely in times of need.

"My friends carry my bag as I find it difficult to walk with a heavy bag up the hill to school" (Boy with locomotor disability, Dimapur).

"The young boys in the neighbourhood, my son's friends, take turns to help my son with his daily needs. As he has grown up, he feels shy if I attend to his personal needs, and I also find it difficult to carry him from the room to the toilet" (Mother of a 24-year-old man with spinal injury, Aizawl).

Livelihood had been an important component of the CBR programmes, linking adults with disability to work and income, instilling self-confidence, and thereby mitigating poverty. This component has brought about a visible change in the lives of persons with disabilities across the three sites where this study was conducted. For those who were linked to self-employment programmes with support for training and start-up funds, trades like piggery, poultry, bee-keeping, livestock rearing, tailoring and carpentry, as well as setting up petty shops in their own area, have helped them to gain respect within their communities by supporting their own families. In Aizawl and Dimapur, people with disabilities were helped with petty business and group livelihood activities such as kitchen gardens and betel nut packing. People have increased incomes and are now being recognised as contributors to society.

"I have extended my betel nut packaging business, which I had been doing before, with a small loan from the group. We all use the same supplier, so it is like a group business" (Woman with locomotor disability, Aizawl).

"From the village level group, we have started a kitchen garden where all the families of the persons with disabilities grow vegetables and once a week we sell them at the local market. Whatever is earned is then distributed according to the contribution each person has made. So now all of us have an income. When we sell at the market, people see us as contributing to our families" (Woman with disability, Aizawl).

The major change was seen in Guwahati, where a DPO has established firm linkages with the local government and claimed access to Right to Food and Work programmes. The names of all persons with disabilities have been included in the list of workers of this programme and the persons with mild to moderate disabilities, as well as family members of those with severe disabilities, have found work from the Government schemes on a regular basis. The continuous lobbying by some active DPOs has ensured that persons with disabilities are included under the poverty alleviation schemes. Besides, DPOs are now linked to the National Rural Livelihood Mission (NRLM) through the local administration.

Limitations to Sustainability

Despite the community sensitisation and individual development of persons with disabilities in all the three sites, there are two areas of concern which need to be highlighted. Two of the major initiatives have been continued, but only with limited success. This is mainly because the systemic and structural initiatives required did not take place, and subsequently persons with disabilities, their families or the DPOs have not been able to sustain them on their own.

The first one relates to access to education, and although there are internal differences across the three sites, continued inclusion within the mainstream education system is restricted, not just due to the geographical terrain but also due to scant resources and poor implementation. During the CBR programme period, school enrolment and attendance of children and young adults had increased, with access to scholarships and transport allowances. While some children with locomotor and visual disability are continuing their education, most of the children with hearing impairments and intellectual impairments have dropped out of school, due to lack of support during the shift from primary to secondary schools which are at a distance from their homes and where the administration and infrastructure are not inclusive or even sensitive towards the needs of youngsters with disability. Continuing sensitisation of schoolteachers and networking with district-level school administrators has stopped. As a result the quality of education for children with disabilities has declined. Teachers cited a number of reasons why students with disability are neglected in their classrooms. While families with limited knowledge and resources, and living in poverty, find it difficult to advocate for their children, DPOs also have been unable to effectively attend to the education needs of children with disabilities, due to poor connections with schools and district-level administrative and support personnel.

The other limited success relates to Disabled People's Organisations (DPOs), organised to collectively work to sensitise communities, and advocate for rights and entitlements along with livelihoods. In the post-programme period, while the livelihood activities have survived to a great extent, the advocacy activities have become very limited. Village-level DPO meetings have become rare, and some DPO members say they are not active as the community is now sensitised. As the leaders of the DPOs lack the vision and skills for advocacy to take the concerns of all persons with disabilities forward, they have not been able to properly include, reflect upon and support these persons to address their developmental as well as care requirements. DPO leaders are individually supporting people to get and renew disability certificates and access other entitlements, as well as referring them to rehabilitation services. The groups that are doing well have very strong leaders, with good contacts in the local administration. In Dimapur and Aizawl, with a majority of Christians having the philosophy of helping their fellow people, DPOs help members with financial support, Christmas gifts etc. Some DPO members expressed difficulty in continuing without the guidance of the CBR staff, while CBR workers felt that the interest in being part of a DPO is waning as many people feel that they have received all possible entitlements. The reasons for weakening of DPOs range from economic concerns around poverty, socio-cultural issues of heterogeneous communities in terms of communication, and different needs and requirements of people with different impairments. However, the block-level DPOs are doing better, with effective leaders having good contacts within the community and the district-level administration.

CONCLUSION

Community-based rehabilitation programmes are looked at favourably by community development organisations and are dismissed by proponents of institutional rehabilitation. However, this model of CBR promoted by CI CBR and supported by Light for the World has attempted to blend medical interventions and other forms of rehabilitation with community-level initiatives, which has ensured the sustainability of the programme in the long run. The cycle of development set in motion by the CBR programme is most prominently visible in terms of the changes - individuals with disabilities have continued to develop beyond the project in terms of self-sufficiency, independence, inclusion in education and within the community, as well as in terms of earning a livelihood. As a result, persons with disabilities have also improved their status within their

families and communities, enjoy better quality of relationships, play an active role in family and community decision-making, and have gained dignity and respect. Knowledge and skills endure within communities, in families and DPO leaders, and are now being extended to others in need of support. With greater acceptance and respect for persons with disabilities within communities, there is more inclusion in everyday activities and decision-making processes. Systemic processes have been activated, resulting in better access to identity cards, aids and appliances, pensions, and locally available subsidy schemes. In Northeast India, where there was little awareness about disability and persons with disabilities, there has been a perceptible shift in terms of inclusion of persons with disabilities in different areas of social living.

Lessons learnt at the end of a long period of CBR interventions have been assessed not only in terms of promotion of rights and community-level awareness and inclusion, but also in terms of shortcomings. People who most benefited from the CBR programmes are those with mild to moderate disabilities, whose needs are relatively easier to address than those of persons with severe disabilities. Most of the initiatives however have left those with severe disabilities at the periphery, with very few of them participating and being included, and few needs being addressed by the CBR programme. In homogenous and closed communities, families with persons with severe disabilities are somewhat helped by community members in terms of care and support. The CBR initiatives have also had limited impact on poverty-stricken families where survival is a major issue, forcing families to discontinue many necessary interventions for the development of their children and young adults. Many of these families have children with severe disability and the progress made during the project period was lost, as their children's condition either relapsed or became worse with advancing age.

The impact of the CBR programme demonstrates that an exit strategy needs to include mechanisms for upgrading skills and information/ knowledge among families, DPOs and communities. This will enable continuity in advocacy for entitlements, rights and systemic changes. The impact assessment exercise has also laid bare the extent of community integration – DPOs are working well in homogenous communities, but the bonding of people has been limited in heterogeneous populations. DPOs need to be empowered to develop a long-term vision and sustainability plan, and build a core of dedicated leaders who are motivated and interested in learning more and looking beyond entitlements. The vision for the DPOs needs to be cohesive and passed from CI CBR to the

training organisation and on to CBR workers and DPOs. There may be a need to extend further hand-holding support to the DPOs and to nurture the ability of leaders with a disability to assert their rights, engage in networking and seek disability convergence into all mainstream development-oriented programmes. If such efforts can be promoted locally and through mentors, there is a greater chance of proactive change continuing within local communities. Lastly, CBR programmes need to find the language and strategies to build a positive attitude towards disability, moving away from deficiency, care and support mode to a rights-based one. This can only be done by inculcating within the CBR programme an orientation towards rights and responsibilities, recognition of diversity and respect for differences among all people in the community, especially the persons with disabilities and the team implementing CBR.

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REVIEW

Implementation of the United Nations Convention on the Rights of Persons with Disabilities in Africa: a Scoping Review

Gwarega Chibaya[1*], Tongai Fibion Chichaya[2], Pragashnie Govender[1], Deshini Naidoo[1]

1. Discipline of Occupational Therapy, School of Health Sciences, University of KwaZulu Natal, South Africa
2. Senior Lecturer in Occupational Therapy, Bournemouth University, United Kingdom

ABSTRACT

Aim: *The UNCRPD is an international treaty that promotes the advancement of the rights of persons with disabilities. This scoping review aimed to map the evidence on strategies employed by countries in implementing the UNCRPD in Africa and the implementation challenges faced.*

Method: *The PRISMA extension for scoping reviews (PRISMA-Scr) was used in this study. Key terms pertinent to the implementation of the UNCRPD in Africa were used to search for literature. Strict eligibility criteria were set and a qualitative data extraction template developed. Two reviewers worked independently to extract and chart data into data extraction forms. An analysis of country reports was also conducted to identify relationships between the African country reports and findings from the studies included in the scoping review. Inductive reasoning enabled the generation of themes. A total of 107 sources were initially retrieved and after a process of screening and exclusion, 31 sources (11 research papers and 20 country reports) were included for inductive analysis.*

Results: The study revealed evidence of implementation of UNCRPD in Africa, albeit limited, especially to the area of education, and employment. However, there are unique contextual limitations in implementation of UNCRPD in Africa. The country reports reflected similar implementation issues to those identified in studies selected for this paper.

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* **Corresponding Author:** Gwarega Chibaya, PhD Candidate in Occupational Therapy, School of Health Sciences, University of KwaZulu Natal, South Africa. Email: gchibaya@gmail.com

Conclusion and Implications: *This calls for African governments to broaden focus on implementation of other articles of the UNCRPD in order to create inclusive societies.*

Key Words: c*ountry reports****,*** ***i****mplementation, scoping review, disability rights, treaty*

INTRODUCTION

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) is the first international human rights treaty aimed at specifically promoting disability rights (United Nations, 2006).The treaty has drawn focus to the exclusionary and oppressive practices against persons with disabilities, which had been overlooked for many years (Byrne, 2012). Literature shows that there are about 1 billion people with disabilities in the world and majority of these are in low- and middle- income countries, with Africa alone having an estimated 40% of the world's persons with disabilities (World Health Organisation, 2011).There are variations in statistical data due to the complexity of defining disability, not only in Africa but also globally (Altman, 2001; World Bank, 2008).

The UNCRPD demands that member states reconsider their domestic legislative and policy frameworks in order to promote disability rights in line with the Convention. Seven African countries participated in the development of the foundational texts of the UNCRPD (United Nations, 2004). In addition to these delegations, there were experts from Algeria, Kenya, and Tunisia, cementing the idea that African participation in the elaboration of the UNCRPD was significant (United Nations, 2004). To date, a total of 46 out of 54 African countries have ratified the UNCRPD (United Nations Treaty Collection). The ratification means member states will be committing to endorsing the Convention by implementing laws, policies, programmes and projects that promote the rights of persons with disabilities in their local contexts guided by the articles of the UNCRPD. Moreover, 33 out of the 46 African countries have ratified the Optional Protocol (United Nations Treaty Collection; Nigussie, 2016).The Optional Protocol provides a mechanism for citizens to directly lodge complaints about violations of the rights of persons with disabilities with the Committee on the Rights of Persons with Disabilities (United Nations, 2006).

The norm implementation of the UNCRPD involves acknowledging disability-based human rights, aligning national disability laws and policies, and social

integration of persons with disabilities based on the Convention's inclusive development mandate (Stein & Lord, 2009). Eleven out of forty-six countries developed or reviewed their national laws or policies on disability after the ratification of UNCRPD (Fernandez, Rutka & Aldersey, 2017). However, there is no African country that has engaged their national policy on disability by adopting the normative framework of the UNCRPD to enable its norm implementation (Combrick & Van Reenen, 2011).

Regardless of African countries' commitment to the UNCRPD treaty, the very same states were working on a draft African Decade of Persons with Disabilities charter, parallel to the process of negotiations and adoption of the UNCRPD. Despite African regional initiatives, the African Decade of Persons with Disabilities 2010-2019 failed to address its objectives due to resource constraints (African Union Commission Department of Social Affairs, 2015).Furthermore, there are some arguments that the UNCRPD compromised the final text by adopting less imperative language proposed by the European Union and failed to address African disability discourse, for example on matters relating to albinism, HIV/AIDS, negative traditional practices and beliefs (Kamga, 2013; Oyaro, 2015). There is a possibility that the rights spelt out in the UNCRPD are contradictory to African views or are not necessary to add to current local disability policies. The continuation of the African Decade when the UNCRPD was already in existence could be an indication that African states still felt that there was a need to address disability issues in an African context.

The UNCRPD seeks to address marginalisation and combat negative attitudes and beliefs against persons with disabilities (McKenzie & Gcaza, 2014). However, current data shows that about 5-10% of children and youngsters with disabilities are enrolled in school, while 70-80% of those in the working age group are unemployed (World Health Organisation, 2011).This most likely leads to poorer health outcomes and higher rates of poverty (World Health Organisation, 2011) and is common among the poorest of the poor.

Despite favourable policy environments in some countries, persons with disabilities in Africa do not fully enjoy their rights since these rights are defined according to how local society views or defines disability (Ncube, 1999; Kachaje, Dube, MacLachlan & Mji, 2014).The lived experience of persons with disabilities in low- and middle- income countries constitutes a significant challenge to the promotion and enforcement of human rights, notwithstanding the signing of the UNCRPD (Lang, Kett, Groce & Trani, 2011). Persons with disabilities are yet to

see if the 2018 African Disability Protocol will redress the current challenges or will ensure a smooth progressive implementation of UNCRPD which enhances inclusive national development programmes.

Inclusion of people with disabilities in employment increases economic self-sufficiency and a country's potential tax base while decreasing demands on social assistance (Banks & Polack, 2014). Conversely, excluding persons with disabilities from development and poverty reduction strategies leads to a loss of productive potential and income for the person and other family members (Mwendwa, Murangira & Lang, 2009).Therefore, Sustainable Development Goals (SDGs) cannot be achieved without the inclusion of persons with disabilities and the UNCRPD Articles provide a platform for comprehensive approaches to sustainable development inclusive of persons with disabilities (United Nations, 2018).

The UNCRPD has been in existence for more than a decade and there are growing concerns about progress of its implementation among the disability movements (Combrick & Van Reenen, 2011). This paper contributes some answers to the recurring question whether the UNCRPD is being appropriately implemented, and to what extent - within the African context- it remains work in progress.

Aim

This scoping review aimed to map the evidence on strategies employed by countries in implementing the UNCRPD in Africa and the implementation challenges faced by stakeholders and the impacts that have been realised. An analysis of the initial country reports on the implementation of the UNCRPD was also conducted to relate these reports to other findings from the literature.

METHOD

Study Design

This study followed the Preferred Reporting Items for Systematic reviews and Meta-Analysis (PRISMA) extension for Scoping Reviews (PRISMA-ScR) checklist and explanation to provide reporting guidance (Tricco et al, 2018). Strict eligibility criteria were set, and a search strategy and search terms were formulated with the assistance of the university librarians. The search terms were entered into WorldCat, the electronic database advanced search, since it combines key

sources of 87 databases. Hand search was conducted on reference lists of each eligible research paper to access relevant peer reviewed research papers on the implementation of the UNCRPD in Africa that could not be indexed on the World Cat global catalogue. Furthermore, the first author contacted the United Nations Humans Rights Office of the High Commissioner to access the United Nations treaty body database which gave country specific approaches on the implementation of UNCRPD among the African countries that had managed to submit their initial country reports by the time of data collection.

A qualitative data extraction template was developed by two reviewers (GC & TFC) who conducted study selection independently. First, title and abstracts were reviewed for inclusion/exclusion criteria evaluation. Studies that met inclusion criteria were included for full text review. Skype call meetings were regularly conducted to discuss progress and resolve differences. The study applied an inductive approach using thematic analysis of data sets.

Search Strategy

A three-step strategy was employed to enable a comprehensive search of information, as shown in Table 1. An initial limited search of two online databases (SpringerLink and MEDLINE) was conducted to enable an analysis of text words that formed part of the keywords. The words synonymous to text word 'implementation", were searched to find more text words. All identified keywords and index terms were used to search across 87 databases. To access some grey literature, UNCRPD reports were accessed from the UN treaty body database. A pearl-growing technique was used in which citations or reference lists of all identified research papers were hand searched (Barnett-Page & Thomas, 2009).

A list of keywords pertinent to the UNCRPD and its implementation in Africa were compiled. Search of these key terms were limited to the period of 2008 – 2019 and peer-reviewed documents. All research papers were included irrespective of the language used. The year 2008 was chosen as a cut-off point, as this was the year in which the UNCRPD and the Optional Protocol became enforceable, and the time when most governments initiated efforts to improve the upholding of the rights of persons with disabilities. Table 1 shows the keywords that were searched and the respective databases as well as the inclusion and exclusion criteria.

Table 1:   Planned Search Strategy

SEARCH STRATEGY ITEM	DATABASES
Information sources	WorldCat - global catalogue of library collections with access to 87 Databases
Search Results	**13 Databases (**WorldCat.org (63), African Journals (25),Electronic Collections Online (5),SpringerLink (5), ArticleFirst (5), Emerald Group Publishing Limited(4), Taylor and Francis Journals (3), BioMed Central (2), ProQuest Psychology Journals (2), ProQuest Research Library (2), ERIC (1), MEDLINE (1), ScienceDirect (1)).
Language Filter	None
Time Filter	2008 – 2019
Spatial Filter	African countries
Libraries	Worldwide
Key words	Kw:("implementation" OR "realization" OR "realisation" OR "enforcement" OR "achievement" OR "Domestication" OR "execution" OR "application" OR " administration" OR "fulfillment" OR "accomplishment" OR "effecting") Kw:("United Nations Convention OR Disability rights") Kw: ("Rights") Kw: ("persons with disabilities" OR "people with disabilities") AND ("Africa").
Inclusion Criteria	State party reports on African countries that have ratified UNCRPD and/or Optional Protocol.
	Full-text available.
	Published studies during the period 2008 and 2019.
	Peer reviewed studies.
	Literature with intervention strategies/barriers/facilitators in the implementation of UNCRPD in African settings.
Exclusion Criteria	Irrelevant database returns/studies not meeting the above criteria.
	Studies outside time span.
	Full-text not available.

Data Extraction and Quality Appraisal

Two reviewers (GC & TFC) worked independently to assess each individual source of evidence obtained from online databases. They hand searched publications as well as assessing the quality of the documents that met the inclusion criteria. These reviewers developed a data extraction and appraisal template as shown in

Table 2, which was organised in a qualitative manner according to the research questions.

Table 2: Example of Data Extraction Template

Author & Year	Title	Country	Purpose/Aim	Key Findings	
				Strategies to promote UNCRPD	**Concerns/challenges encountered in implementing UNCRPD**

The template included the name of the author, year of publication, topic of study, country where the study was conducted, aims/purpose and the key findings in relation to the scoping review objectives. The involvement of two reviewers and use of the same data extraction template helped to confirm requirements of scoping reviews in minimising risk of bias.

Eighty-seven databases were searched through the WorldCat catalogue. Thirteen of these 87 databases yielded results of 87 studies. The UN Humans Rights Office of the High Commissioner provided an additional 20 country reports, giving a total of 107 records. Of the 87 studies retrieved, 7 were duplicates (see Fig. 1).

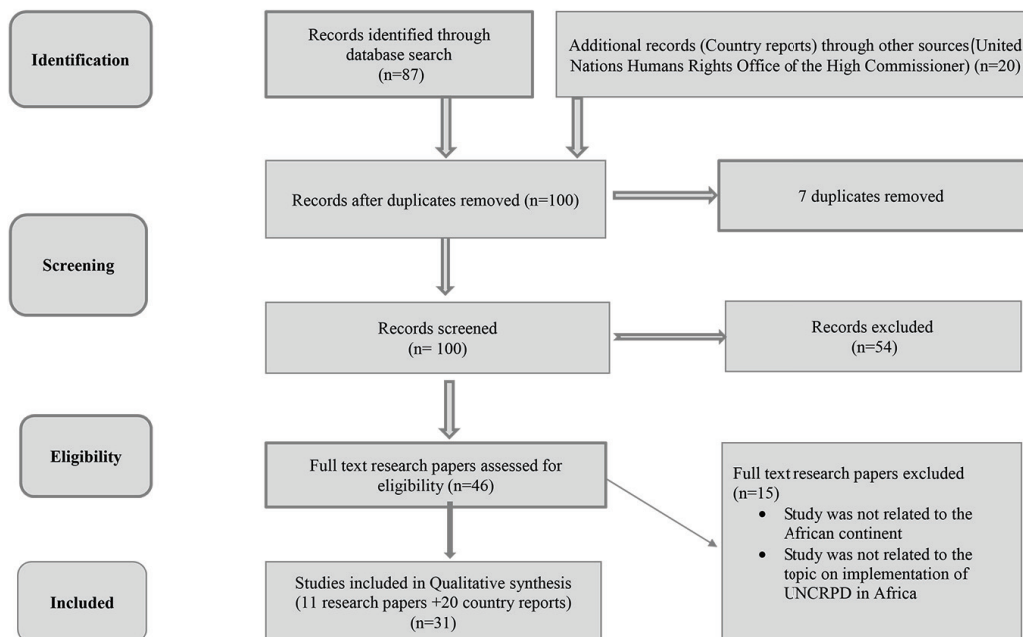Fig 1: Flowchart of Study Selection according to PRISMA Statement

Figure 1 illustrates the processes involved in selecting studies for inclusion in this review. Seven duplicates were removed. The two independent reviewers screened each abstract of the 100 records, resulting in 54 exclusions. Fifty-four studies were not related to the African continent and the topic of discussion. Forty-six studies were assessed for eligibility, of which 31 (11 studies and 20 country reports) were selected for inclusion in the qualitative synthesis.

RESULTS

The identified pattern of data was thematically analysed and interpreted. Individual study findings from 11 records were synthesised into codes, categories and themes, with a separate analysis of 20 country reports. Table 3 shows the categories and the emerging themes from the review, with the number of supporting documents for each category discussed. The categories and themes are discussed subsequently.

Table 3: Themes and Categories

THEMES	CATEGORIES	NUMBER OF STUDY REFERENCES PER CATEGORY
Piecemeal implementation of the UNCRPD in Africa	Some legislative amendments and partial implementation	4
	Gaps in monitoring compliance to the UNCRPD	3
	Limited resource allocation	5
Contextual limitations for implementing the UNCRPD in Africa	Socio-cultural and infrastructural barriers	2
	Lack of political will	5
	Silence of persons with disabilities and inactive Organisations of Persons with disability	3
	Disability is complex and misunderstood	4

Theme 1: Piecemeal Implementation of the UNCRPD in Africa

This theme relates to existing intervention strategies that have been used for the implementation of the UNCRPD in African settings. There is some evidence of legislative amendments and approaches to address education and employment of persons with disabilities. The available evidence reveals that the implementation

of the UNCRPD in Africa is mainly limited to few articles of the Convention, particularly the ones on education and employment; hence the use of the term 'piecemeal implementation'.The following sub-sections provide a discussion on each of the categories that make up this theme.

Some legislative amendments and partial implementation

There is evidence of attempts by the governments to improve the rights of persons with disabilities in Africa through legislation. Most African countries ratified the UNCRPD and are therefore legally bound to implement its obligations (Virendrakumar, Jolley, Badu & Schmidt, 2018). In addition, to date, just over 10 countries have introduced new legislation or reviewed existing legislation to comply with the UNCRPD. Southern and Western African countries are mainly among the few states that have made legislative amendments and there is a significant absence of legislative changes to align with the UNCRPD in Northern and Central African countries (Virendrakumar et al, 2018). Some countries like Malawi, Zambia, Tanzania, South Africa and Nigeria have more recent legalisations that are explicit about preventing discrimination against persons with disabilities in employment; for example, the Employment Services Act of 2014 and the Discrimination Against Persons with Disabilities (prohibition) Act of 2018 in South Africa and Nigeria respectively (Basson, 2015;Virendrakumar et al, 2018). There is evidence of processes and practices of inclusive education and existing protection of persons with disabilities in the employment sector against unfair dismissal (Chataika, Mckenzie, Swart & Lyner-Cleophas, 2012; Basson, 2017; Murungu, 2015).Legislations supporting education of children with disabilities are an intrinsic part of laws and policies that seek to domesticate the UNCRPD. For example, the governments of Lesotho, Namibia, Nigeria, and Malawi have policies that address inclusive education (Chataika et al, 2012; Murungi, 2015).However, programmes supporting inclusive education in Africa, for example, the Disability-Inclusive Education in Africa Programme established by the World Bank and USAID, are mainly being implemented by non-governmental organisations and development agencies (World Bank, 2018). Some disability activists are wary that African governments may negate their responsibilities for adhering to the UNCRPD as disability matters can be easily construed as charity.

Gaps in monitoring compliance to the UNCRPD

There is some evidence of monitoring compliance of the UNCRPD. In South Africa, the South African Human Rights Commission (SAHRC) plays a role in monitoring the implementation of the Equality Act and disability rights, including at the international level (Holness & Rule, 2015). Furthermore, SAHRC has pushed the South African government to finalise its progress report on the implementation of the UNCRPD as well as progress on implementation of recommendations made by the Equality Court. In 2017, the Southern Africa Federation of the Disabled (SAFOD) facilitated a training for Disabled People's Organisations (DPOs) from its member states, to equip them with knowledge and skills for developing parallel UNCRPD reports as a way of improving monitoring compliance with implementation of the Convention (Holness & Rule, 2015). According to Holness and Rule (2015), countries like Namibia and Botswana have government departments that are responsible for disability affairs. However, this limits effectiveness in monitoring compliance because such entities are not independent bodies. Similarly, the law in Malawi stipulates the establishment of a National Advisory and Coordinating Committee on Disability Issues. This has only been reinstated recently, and some progress has been noted with the development of a national disability monitoring and evaluation framework (Ngomwa, 2019). These initiatives need to be accelerated in order to improve monitoring compliance among African countries. Furthermore, signing of the UNCRPD Optional Protocol could increase member states' commitment to addressing the rights of persons with disabilities. Unfortunately, most African countries have not ratified the UNCRPD Optional Protocol, while some were slow in taking this decision; for example, by 2017 only three countries had signed the Optional Protocol in southern Africa (Chichaya, Joubert & McColl, 2019).

Limited resource allocation

Most African governments have allocated financial resources, though inadequate, to support the participation of country representatives at the UNCRPD meetings during norm acceptance and country reporting held at various international fora (Mwendwa et al, 2009; Onazi, 2016). However, there are many competing demands against scarce resources in Africa, which makes it difficult to allocate enough resources towards the full implementation of the UNCRPD (Mwendwa et al, 2009). African countries lack human, financial and physical resources to implement the UNCRPD (Chataika et al, 2012). They further stated that where

resources are available, these resources seem to be concentrated in the urban areas, whereas the majority of persons with disabilities in Africa live in rural areas. The rights of persons with disabilities are dealt with in a fragmented fashion, often in disparate pieces of legislation (Basson, 2017) because many countries believe that they do not have the financial and infrastructural capacity to actually implement the policies (Fernandez et al, 2017). Non-profit organisations for disability fund specifically targeted services for persons with disabilities to implement aspects of the UNCRPD, but this is only to a limited extent and cannot replace the responsibilities of governments(Mwendwa et al, 2009).For example, CREATE, a non-profit organisation in South Africa, funded workshops on education and advocacy on forwarding discrimination claims in the Equality Court (Holness & Rule, 2015), while the United Kingdom Department for International Development (DFID)funded the community-based rehabilitation and mainstreaming programmes of persons with disabilities(Mwendwa et al, 2009).According to Mwendwa et al (2009), the DPOs have failed to convince the local business communities and government about the benefits of investing in persons with disabilities. There are reports of government ministries being less collaborative in addressing disability and development issues, with disability issues remaining on a low profile with less priority in funding allocation (Chataika et al, 2012).

Theme 2: Contextual Limitations for Implementation of the UNCRPD

There is a noticeable "disconnect" between the rights of persons with disabilities guaranteed in the UNCRPD, and its translation into policy development and implementation (Lang, Schneider, Cole, Kett & Groce, 2017). Theme 2 relates to the challenges encountered in implementing the UNCRPD in Africa. There is a strong indication that socio-cultural and infrastructural barriers, lack of political will, the silence of persons with disabilities and inactive DPOs negatively affect the implementation of the UNCRPD in Africa. The following sub-sections present and discuss the categories that informed Theme 2.

Socio-cultural and infrastructural barriers

Attitudinal, environmental and institutional barriers prevent persons with disabilities from participating fully within contemporary society(Mwendwa et al, 2009).Attitudinal barriers include negative and insensitive behaviour displayed by frontline workers like clerks, security guards including civil servants

designated to assist persons with disabilities, and, for example, the pervasive attitude displayed by frontline workers at Equality Courts in South Africa was found to negatively impact on the ability of persons with disabilities to access litigation service (Holness & Rule, 2015). Furthermore, participation of persons with disabilities in community development has been affected by negative social attitudes and cultural beliefs held by some of the general community members, as for example the case of persons with disabilities in many African countries who experience limited inclusion in activities of daily living (Mwendwa et al, 2009). Environmental barriers are physical obstacles in the environment that affect accessibility; for example, accessibility in shopping malls and public service centres have been reported to be inaccessible in many parts of Africa (Holness & Rule, 2015).In addition, Holness and Rule (2015) stated that while the provision of mobility aids such as wheelchairs can improve independence of persons with disabilities, the use of these aids is dependent on the removal of the existing environmental barriers. Institutional barriers in the form of inflexible procedures or policies have been reported to hinder participation of persons with disabilities; for example, when news agencies do not put provisions to make news available in formats that are accessible to persons with visual and hearing impairments (Nikoltchev, 2014).

Lack of political will is subtle

There is generally a subtle lack of political commitment to implement the UNCRPD comprehensively in Africa, evidenced by lack of responsive disability laws and policies to domesticate the UNCRPD (Fernandez et al, 2017) and delayed country reports on the UNCRPD (United Nations Treaty Collection). The disparity between treaty ratification and domestic implementation can be considered as lack of political commitment among member states to internalise the treaty norms, possibly due to a lack of political will (Onazi, 2016).Furthermore, the delays in submission of UNCRPD reports demonstrate lack of political will, considering that only one African country submitted the initial country report on time, some missed the submission due date by three or more years and others have not submitted their reports to date (United Nations Treaty Collection). A positive change to implement the UNCRPD requires a strong political will and the capacity to defend re-allocation of scarce resources against competing demands. However, lack of good governance, lack of political will and policy context makes it difficult for many low- and middle- income countries to promote disability rights (Chataika, et al, 2012).At the continental level, Lang et al(2017) have shown that

the recent 9 key documents reviewed on international development initiatives do not consistently and comprehensively address disability issues. According to Lang et al (2017), policy-makers do not perceive disability issues as a key policy priority in the context of Africa's wide social and economic policies.

Silence of persons with disabilities and inactive organisations of persons with disabilities

The development of 9 African Union policies at continental level missed the inclusion of persons with disabilities or their organisations as proactive and important actors in the process of policy development(Lang et al,2017). Unfortunately, there are no traceable guidelines from DPOs on how to work with stakeholders in national or district development plans/strategies (Mwendwa et al, 2009).In Uganda, the disability movement was found to be disengaged from working with other stakeholders in developing disability policy, and lacked tools and benchmarks to bring the government to account over its commitment to disability rights (Mwendwa et al, 2009; Lang et al, 2017).The DPOs have also struggled to convince civil authorities of the benefits of investing in persons with disabilities, for example in Botswana and Uganda (Mwendwa et al, 2009).However, external factors such as lack of opportunities to education and employment significantly silence the voices of persons with disabilities (Chichaya, Joubert & McColl, 2018).

Disability is complex and often misunderstood

Nine African Union documents reviewed in the domains of education, health, employment, social protection, and general development had scant references to any specific definition of disability (Lang et al, 2017).Furthermore, the reviewed documents did not provide objective criteria on who should be targeted as a person with disabilities and who is responsible for implementing programmes to address disability issues. There is a lack of consensus agreement on most effective implementation strategies, especially in low- and middle- income countries (Mwendwa et al, 2009). In addition, many governments do not know how to replicate domestic enforcement mechanisms in the international sphere due to the lack of agreement of clarity on what international enforcement means (Onazi, 2016). Developing implementation strategies is also hindered by lack of reliable and relevant data on the nature and prevalence of disability. Most governments still approach disability as a specialist issue which can be addressed through segregated institutional provision, especially health services, rather than effective

inclusion and mainstreaming (Mwendwa et al, 2009). The confusion in Uganda where disability activists lobbied for the creation of more special schools for children with visual impairment and hearing impairment through the president, against the ministry's plans and budgets for inclusive education, is a sign of lack of agreement and understanding of the most effective strategies and modalities in addressing complex disability issues (Mwendwa et al, 2009).In addition, 10% of children with disabilities attend schools in segregated settings in Africa since most governments treat disability as a specialist issue, thereby contradicting inclusive education (Chataika et al, 2012).

Findings from the analysis of African country reports

An analysis of country reports was conducted in order to identify any relationships between their contents and literature findings from this scoping review. The findings relate to the objective, which sought to analyse the UNCRPD country reports that have been submitted by African governments. Twenty country reports were analysed in terms of meeting the due date for submission (see Table 4), documenting the involvement of stakeholders in preparation of the report and the content of the report concerning the implementation of the UNCRPD.

Table 4: List of Countries and the UNCRPD Submission Time

COUNTRY	UNCRPD REPORT SUBMISSION TIME
Ethiopia	On time
Angola	1 year overdue
Mauritius, Ghana, Malawi, Kenya	2 years overdue
Gabon, Uganda, Seychelles, Sudan, Algeria, Morocco, Senegal, Togo	3 years overdue
Djibouti, Rwanda	4 years
Niger, South Africa	5 years
Burkina Faso	7 years
Mali	9 years

From Table 4, one learns that only 20 countries submitted their initial reports out of 54 African countries that have ratified the UNCRPD. This negatively reflects on the African governments' commitment to upholding the rights of persons with disabilities in an accountable manner. Among the countries that submitted their initial reports, only Ethiopia submitted the report on time. Most of the country reports were overdue by three or more years as shown in the Table. No country has provided the second report as per Article 35, paragraph 1 of the

UNCRPD, which requires state parties to submit progress reports at least every four years after submitting the initial report (United Nations, 2009). This delay may be attributed to factors such as lack of political will; the lack of capacity and expertise; lack of relevant disability statistics; and, lack of consensus among stakeholders. These factors were identified in the documents that were analysed in this study.

Involvement of stakeholders in preparation of the UNCRPD country reports

Article 35 of the UNCRPD encourages constructive engagement of all disability stakeholders to enhance the quality of reports. The reports should include explanation of the procedures adopted to consult and access all the disability stakeholders (United Nations, 2009).The documentation of the consultation processes involved in the country reports were analysed and rated: Class1 - comprehensive consultative process documented, Class 2 - generalised consultative process documented, and Class 3 - little consultative process documented. Comprehensive consultative process documentation refers to when the report shows names and number of stakeholders especially the DPOs involved, timeframe and detailed processes involved. Generalised consultative process documentation is when a report contains names and number of stakeholders with no detailed process and timeframe involved. The little consultative process documentation means there is no specified methodology used to collect and synthesise data, no indication of names of organisations of persons with disabilities involved and timeframe of processes involved. Table 5 shows the classification of country reports used in this study.

Table 5: Rating of how the Stakeholder Consultation Process was documented in the Report

RATING OF HOW THE STAKEHOLDER CONSULTATION PROCESS WAS DOCUMENTED IN THE REPORT	COUNTRY REPORT
Class 1: Comprehensive information on consultative process	South Africa, Malawi,
Class 2: Generalised information on consultative process	Angola, Algeria, Uganda, Tunisia, Seychelles, Senegal, Morocco, Mauritius, Djibouti
Class 3: Little information on consultative process	Rwanda, Togo, Mali, Niger, Ethiopia, Sudan, Kenya, Ghana, Gabon,

From Table 5 it appears that documentation of the stakeholders involved in the preparation of the report was inadequate in most of the country reports. Only two of the countries were categorised as Class 1. These countries documented comprehensive consultative processes. Malawi even provided the list of all organisations consulted as an appendix to their country report, which improves the quality and validity of their report (United Nations Treaty Collection). Country reports that were placed in Class 2 provided generalised or little information on the consultative processes and procedures done, and this negatively affects the objectivity and validity of how the UNCRPD is being implemented. For example, the Mauritius report did not state the names of DPOs involved during the two workshops and whether they were directly involved and how the data was collected (United Nations Treaty Collection). Reports in Class 3 were considered to have little information documented on how the DPOs were involved and this raises questions on whether there are capacitated and active DPOs who are participating in governance processes within these countries. For example, Gabon's report mentioned that they used various committee members in their methodology (United Nations Treaty Collection), hence it was categorised as Class 3. The reports with generalised or little information on the methodology used could be due to non-participation of DPOs because of limited capacity and resource constraints. South Africa's country report corroborated that capacity and resource constraints hinder the extent to which DPOs participated in the development of the country report (Basson, 2017).

Common Findings from African UNCRPD Country Reports Content

The country reports focused more on the national policy framework which strives to promote disability rights, without providing any detail to reflect the actual implementation of UNCRPD at the grassroots level. For example, South Africa's national policy framework promotes inclusive education but new segregated Learners with Special Education Needs (LSEN) schools are under construction. The LSEN schools concept is contrary to inclusion of children with disabilities into the mainstream system. It further perpetuates the view that children with disabilities should be kept separate, which is contrary to the White Paper 6 (Murungi, 2015). The Tunisian government endorsed inclusive education but supports specialised education and training (Murungi, 2015). The country reports relate well to what has been alluded to in the literature in terms of implementation strategies and challenges encountered. There is evidence of disjointed implementation of the UNCRPD in Africa while lack of relevant

disability statistics, resource constraints, and societal attitudes remain important areas that need to be addressed.

Most country reports provide some information on the country's constitution or old policies that predate the UNCRPD as long as they have an element of disability rights advancement and not necessarily the changes or actions taken to domesticate the UNCRPD. There is a paucity of evidence within the policies drafted after the ratification of the UNCRPD in most of the country reports to demonstrate that the policies were informed by the UNCRPD. The complexity of disability and lack of enforcement mechanisms could affect how the UNCRPD informs policy development and subsequent implementation (Onazi, 2016).All 20 country reports have acknowledged the continued vulnerability of persons with disabilities residing in rural villages, hence the need for systematic and comprehensive approaches.

Recommendations

There is a need to strengthen the current implementation strategies of the UNCRPD through accelerating legislative amendments which are informed by the UNCRPD, improving monitoring compliance and increasing resource allocation. This can be achieved through strengthening the level of engagement of DPOs and persons with disabilities in legislative amendments, budget and public finance management process. Enforcement mechanisms of the UNCRPD that are direct and easy to comprehend need to be developed and could be built on the ongoing monitoring process to the UNCRPD committee (Cote & Kukava, 2019). Clear and direct UNCRPD enforcement mechanism will facilitate the development of a reporting template that is treaty-specific. This will enable the production of more precise country reports.

Instead of the African countries channelling more resources towards achieving the same goal by developing continental disability drafts, adopting the UNCRPD would cut down costs with the same outcome. The African governments should strengthen political commitment to publicly acknowledge the UNCRPD, align national disability laws and policies, and integrate persons with disabilities within social and development issues.

Limitations

There are literature gaps in the implementation of the UNCRPD. Most of the

published literature is within the South African context covering few implemented Articles of the UNCRPD. This is a potential source of research bias given the size of the African continent. The country reports analysed were all initial reports, hence limited progress or challenges were reported within the African context.

CONCLUSION

The findings of this paper have shown that there are gaps related to the actual implementation of the UNCRPD at the grassroots level in African societies due to contextual challenges. These contextual challenges include socio-cultural and infrastructural barriers, lack of political will, complexity of disability issues, notable decreased effectiveness of the disability movement and lack of resources. However, there is evidence of fragmented implementation of the UNCRPD in Africa as indicated by elements of inclusion of persons with disabilities with focus on education and employment. This calls for African governments to broaden focus on implementation of other Articles of the UNCRPD, and to effectively ensure collaboration with all stakeholders to create inclusive societies.

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BRIEF REPORTS

Appropriate Screen Time Use to Prevent Speech and Language Delay in Toddlers during the Covid-19 Pandemic: A Brief Report

Vrinda R[1], Krishna A R[1], Suja Kurian Kunnath[1*]

1. National Institute of Speech and Hearing, Trivandrum, Kerala India

ABSTRACT

With the COVID-19 lockdown and other limitations, screen time has increased for everyone, even young children. Children's screen use has a deleterious influence on a variety of cognitive functions, including language delay. Various Paediatrics organizations have noticed these harmful impacts, and suggestions for parents were released to limit screen usage. These agencies have provided suggestions on the duration of screen usage for specific age groups. This study tries to address screen time from a qualitative standpoint. Suggestions for successful ways to participate in screen time are presented. Interactive screen time, including co-viewing and enough language engagement, may assist to mitigate the negative effects of screen time on language development. The screen has its own restrictions and several severe repercussions if they are exceeded. As a result, wherever feasible, screen time should be avoided, and language-rich quality time with children should be prioritized.

INTRODUCTION

The outbreak of the Covid-19 pandemic has changed people's lives all over the world. Everyone is adjusting to a new 'normal' while simultaneously using more technology. Adults and children are dependent on the internet for their work, studies and entertainment. As a result, their physical activities have reduced and screen time has increased (Schmidt et al, 2020). The initial research related to Covid 19 has focused mainly on the epidemiology, risk modelling, pathophysiology, and clinical features (Andersen, Rambaut, Lipkin, Holmes & Garry,2020; Lan et al, 2020); later reports have focused on the impact that the Covid 19 related

lockdown has had on various aspects of life including the economy, mental health, increased digital screen time and related issues such as myopia, obesity, disturbed sleep, and so on (Maital & Barzani, 2020; Schmidt et al, 2020; Wong et al, 2021; Singh & Balhara, 2021). However, the impact of high screen time on the speech and language development among toddlers and pre-schoolers during the Covid pandemic has largely gone unreported in research.

Screen time is the total time spent per day in viewing screens such as the mobile phone, TV, computer, tablet, or any hand-held or visual device (Indian Academy of Paediatrics, 2021). Children spend more time on screens as a result of the closure of day-care centres and/or preschools, and have fewer opportunities to interact with other children. This has a negative impact on language development, especially among very young children. Kuhl, Tsao and Liu (2003) investigated language learning in non-social contexts by presenting the stimulus through non-interactive media such as speakers on video and audio recordings. Their study found that language learning, particularly phonemic and phonetic repertoire, was not developed when presented through non-interactive media. Social interaction has been shown to be important in natural language learning (Robb, Richert & Wartella , 2009; Conboy & Kuhl, 2011; Conboy, Brooks, Meltzoff, & Kuhl, 2015). The current report discusses the negative effects of non-interactive screen time, which is defined as passive viewing of a screen without any active cognitive or communicative involvement from the child. The advantages of using interactive screen time are also discussed in greater depth.

Non-interactive Screen Time and Language Development: How is it Associated?

Excessive non-interactive screen exposure in very young children and its undesirable outcomes are mentioned in numerous studies (Duch, Fisher, Ensari, & Harrington 2013; Domingues-Montanari, 2017). Increased screen time has been linked to a variety of detrimental effects including attention issues, obesity, visual problems like myopia, deprivation of sleep, eating problems, reduced social interaction and delayed language development (Nunez-Smith, Wolf, Huang, Emanuel & Gross, 2008). In a survey on parents' awareness about the impact of screen time on communication in toddlers (Vrinda, Maria, & Swathi, 2021), speech delay was the least reported impact and visual problems were the most reported impact. This indicates the parents' lack of awareness about the issue. In the same study, 75.5% of the parents thought that it was easy to manage their children by allowing them to watch a screen. Many parents believed that by

exposing their children to nursery rhymes and cartoons, the children would learn to speak. Although studies have shown that older children may learn vocabulary simply by watching television, younger children can only learn vocabulary when supported by social interaction (Roseberry, Hirsh-Pasek, Parish-Morris & Golinkoff, 2009). In the study by John et al (2021) in Kerala (the southernmost state of India), almost half of the 189 children in the study had inconsistent supervision by parents. According to this study, unsupervised or inconsistently supervised screen time is associated with suspected cognitive delays, including communication, social skills, self-care, attention span and play in preschoolers.

In terms of communication, non-interactive screens are always one-sided and do not require the child to respond. Also, when screen time increases, the chances of reduced parent-child interaction are high (Mistry, Minkovitz, Strobino & Borzekowski, 2007; Tanimura, Okuma & Kyoshima, 2007; Radesky, Schumacher & Zuckerman , 2015). Human to human interactions have a strong influence on a child's language development for both speech perception and production (Kuhl, 2004). Passive viewing of excessive television or screen time will diminish parent-child interaction, which will have a substantial impact on a child's language development (Tanimura Okuma & Kyoshima, 2007). In a study of two-year-old Korean children (Byeon & Hong, 2015), the average daily TV viewing time of more than 2 hours was linked to language delay. Apart from language development, the other negative impacts associated with high screen time for young children include delays in cognitive and social development (Barr Lauricella, Zack & Calvert,2010).

When it comes to toddlers' language development, it is not only direct TV viewing but also background television viewing that has been found to disrupt 12- and 24-month-old children's sustained toy play. It also decreases the quality and quantity of parent-child interactions when compared to interactions that take place with the television turned off (Schmidt Pempek, Kirkorian, Lund & Anderson, 2008; , Pempek, Murphy, Schmidt & Anderson, 2009). Parental screen time should be limited as well, because parental interactions with young children have been shown to decrease significantly as a result of parental use of mobile phones (Radesky et al, 2014). As a result, it appears that parental involvement with electronic devices may reduce the quantity and quality of parent-child interactions, which are critical for the development of cognitive skills, particularly language and executive function (Anderson & Subrahmanyan, 2017). Screen time replaces time spent interacting, thereby reducing communication opportunities.

Interactive Screen Time and Language Development: How is it Associated?

Recent evidence reveals that it is not watching the screen that hampers children's language development, but the lack of interactivity during screen time. A study on English-speaking toddlers, aged 24 to 30 months, on novel verb learning in three ways - live interaction training, socially contingent video training over video chat, and non-contingent video training - revealed that children learned new verbs only during socially dependent interactions (live interactions and video chat) (Roseberry, Hirsh-Pasek, & Golinkoff, 2014). This implies that the screen itself does not impede children's language development; rather, the lack of interactivity during screen time is the problem. Roseberry et al, 2014; Myers LeWitt, Gallo and Maselli, 2017 state, based on their research, that children can learn language through technology that promotes social interaction. The content of the media and the context of viewing, such as co-viewing, are the most important factors influencing language development on the screen (Nathanson, 2001). This can be explained as the reason behind offering speech language intervention services via telepractice. Age-appropriate quality television programmes with specific educational goals can provide a good pathway for children as young as two years of age to develop early language and literacy skills. These programmes also promote cognitive skill development, such as imaginative play (Thakkar Garrison & Christakis, , 2006). According to research, interactive media associated with contingent responses from adults help children memorise learned information. These contingent responses, combined with age-appropriate content, timing, and intensity of action, can aid in the acquisition of new words (Radesky Schumacher & Zuckerman, 2015).

Effective Use of Interactive Screen Time to Support Language Development

Both the World Health Organisation (2019) and the American Academy of Paediatrics (AAP) (2016) have advised children to limit their screen time. The Indian Academy of Paediatrics (IAP) recently released screen time guidelines for parents. Delayed speech was mentioned as one of the negative effects of excessive screen time for children. According to the IAP (2021), children under the age of two should not be exposed to any type of screen, with the exception of occasional video calls with relatives. Screen time for children aged 2 to 5 years should not exceed one hour in a day; the less time spent on screens, the better (Twenge & Campbell, 2018). Recommendations by various agencies on restriction of screen time suggest no screen time till 2 years of age. The reason is that children below 2

years of age will have difficulty in transferring the information from a 2-D object on the screen to a 3-D object in the real world; this phenomenon is called video-deficit (Strouse & Troseth, 2014).

According to a report from Kerala, where the literacy rate is very high (96.6% as per the Census of India, 2011), the majority of parents were aware that screen time should be limited; however, they were unaware of the established guidelines, and hence proper screen time restriction for their children was not implemented. Only 25 of the 200 participants had set a screen time limit of less than one hour, and 90 had not set any guidelines at all (Vrinda et al, 2021). Despite all of the recommendations and guidelines to restrict screen time, most parents have found it difficult to impose limits due to the lockdowns during the Covid-19 pandemic. The following are some pointers to help caregivers support their children's language development even when they are watching screens:

1. The most important piece of advice is to co-view. Co-viewing strengthens the parent–child bond and allows the parent to monitor the content that the child is watching. However, co-viewing alone will not aid in the development of language. Along with co-viewing, parents could describe what they see on the screen.

2. The various language stimulation techniques used during shared reading can be used in the context of screen time. The screen's visuals can be described in simple language so that children can understand what they see.

3. Recognise and respond to children's efforts to communicate. In the meantime, ask simple questions, extend and broaden their utterances. Expansion and extension will aid in increasing the average length of utterances.

4. Try to relate what is seen on the screen to what is seen in real life. For example, if a girl is seen eating a banana on the screen, the parents should assist the child in recalling previous instances of eating a banana or show the child a banana at home. If a child points to a flower, parents can encourage him or her to say the name of the flower, where it can be found, describe the smell, and so on. With more verbal children, parents can encourage imaginative play and role play scenarios based on the cartoons they watch. For example, if the child enjoys the "Tom and Jerry" cartoon, parents can play the role of Tom and the child can act as Jerry, or vice versa, using appropriate dialogue.

5. Avoid background screens while spending quality time with one's children. Caregivers' attention may wander when the screen is playing in the background and this could affect the quality of the parent-child interaction. Also, exposure to excessive background TV has been shown to have a negative impact on language development, attention, and executive function in children under the age of five (Zimmerman & Christakis, 2007; Schmidt et al, 2008; Kirkorian et al, 2009).

6. Caregivers can engage in games involving objects similar to those seen in the media, such as building blocks or catching balls. Introduce various strategies to extend children's media learning, such as acting out a story based on the content of a recent TV show they watched, or labelling the colours of common household items they learned from an app.

7. Parents should be aware that repetition can help children learn. For example, if the child learns about counting from a TV show, he or she should focus on counting on multiple occasions, while watching different shows and in real-life situations. This will also help in generalisation of the learned skill.

8. Digital books are becoming more popular. E-books can be encouraged instead of animated videos, as e-books are proven to have many of the benefits of traditional printed books (Reich et al, 2019). An e-book is like a traditional storybook in several ways. It contains book elements like a table of contents, sections, and pages, and it is organised around a subject or theme for communication functions (de Jong & Bus, 2003). The e-book's interactive features can help with vocabulary/word learning, print awareness, word decoding, and reading fluency scaffolding (Paciga & Hoffman, 2015).

    Visual and audio effects from e-books and animation help in story comprehension and event sequencing in pre-schoolers (Radesky et al, 2015). Hence, along with entertainment, screen time supports language development in children, when quality content is co-viewed and discussed with a parent or caregiver (Linebarger & Walker, 2005).

9. Early literacy can be promoted by using interactive 'learn-to-read' apps and e-books to practice letters, phonics, word recognition and reading.

10. Limit the caregivers' screen time, because parent-child interaction will be limited when the caregivers' screen time is high. This will have a negative effect on the child's language development due to the poor language stimulating

environment the child is in. Provide a language-rich environment for the child's language development.

Remember the screen has its own limitations and there are many other detrimental effects if the limits are exceeded. So, whenever possible, avoid screen time especially during meals and 1 hour prior to sleep, and enjoy language-rich quality time with one's young children.

CONCLUSION

The screen is not in itself the villain responsible for children's delayed language development; rather, the lack of interactivity during screen time is the problem. Interactive co-viewing may solve this problem to a certain extent. However, the screen has its own limitations, so screen time needs to be restricted. Limiting toddlers' screen time to less than 2 hours per day would improve their cognitive abilities. Also, caregivers should spend some quality screen-free time with their children and play physical games with them. It is strongly recommended that the screen time guidelines are revised to include suggestions for parents of young children to choose age-appropriate quality content, as well as to encourage co-viewing in order to improve parent-child interaction. Raising public awareness about the effects of screen time on language development and using screen time effectively to help develop language should also be considered, as studies have shown that parents are unaware about the harmful effects of screen time on language development and about the recommendations to limit screen time.

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LETTER TO EDITOR

Dear Editor,

Time to Refocus: Rehabilitation Perspective on Meeting the Needs of the Indian Population

In recent years the Indian healthcare system has undergone rapid changes in the way services are delivered. There has been an increase in investment mostly in drugs and pharmaceuticals, machineries and equipment used in diagnosis and treatment of endemic and communicable diseases (Joseph & Ranganathan, 2016; Ganesan & Veena, 2018). The focus on communicable diseases has side-tracked the growing needs of the population living with chronic health conditions that, in the past, had high mortality rates such as stroke, road traffic accidents, and cancer. Furthermore, several researchers Sadikot et al, (2004); Ramachandran, (2007); Dandona et al, 2008; Kaul et al, (2009); Herman, (2017); Sharma & Ganguly, (2018) have shown that there is an increase in the proportion of older adults, people living with multi-comorbidities, chronic non- or slowly progressive conditions such as Type 2 diabetes, chronic obstructive pulmonary disease and arthritis, which keep them from leading productive lives. A study by Agarwal (2020) showed that in India, 6% of 1.36 billion people (around 81.6 million) are over the age of 65 years. Without robust health policies and direct investment to improve the health and quality of life of this growing section of the population, India will face premature deaths and have large numbers living with poor quality of health. Bloom et. al. (2014) estimated that by 2030 non-communicable conditions will cost the Indian economy over $4.3 trillion in terms of loss in productivity and healthcare expenditure, which is twice the country's gross domestic product.

Rehabilitation is one main way to improve the health-related quality of life of this population and to meet Goal 3: Good Health and Well-being, of the Sustainable Development Goals adopted by the United Nations General Assembly (2015). In India, classified as a lower-middle-income country by the World Bank, rehabilitation services are scarce and are offered mostly in the urban areas (Fantom & Serajuddin, 2016). The healthcare services are barely able to handle the dual burden of controlling infection and coping with the growing population living with non-communicable conditions and comorbidities.

The recent COVID-19 pandemic has revealed the gaps in the current healthcare system provided by the State and the Central Governments. It has perhaps

presented an opportunity to develop a system on 'what could have always been attainable but was never implemented'. Global estimates of the need for rehabilitation, reports that, around 2.41 billion people (95% Uncertainty Interval 2.34, 2.50) in the world are in need of rehabilitation and highlights the burden of non-communicable diseases (Cieza et al, 2021). In view of the global estimates, this letter to the editor provides a broad perspective on the current state of rehabilitation within the Indian healthcare system and suggests possible avenues to better meet the demands of the Indian population.

1. Redefining the role of rehabilitation: Rehabilitation services, specifically the role of the physiotherapists, have to change from crisis intervention to community health so as to meet the needs of the population. Typically, physiotherapists are focused to support people to maximise their function (e.g., improve walking post-stroke) and/or return to pre-injury levels (e.g., post-fracture) wherever possible. However, this constitutes a small proportion of people to whom the services are available, as the services are concentrated in towns and cities. Consequently, the traditional physiotherapy approach needs to be recalibrated to meet the demands of those who often live in remote and rural areas. Rehabilitation professionals can, for instance, play a pivotal role in supporting, educating, and empowering people and communities to take charge of their own health. Professionals can engage with communities in local adaptation of evidence-based best practices, develop educational materials, and strengthen community-based rehabilitation programmes in the areas of prevention, health promotion, self-management, ergonomics, and quality of life, while also addressing barriers in society related to access to these services. Access to rehabilitation services has to move from being a 'privilege' to a basic health need.

2. Education of healthcare professionals:

2.1. Training: It is important that the next generation of rehabilitation professionals is sensitised and trained to meet the needs of people with non-communicable conditions such as obesity and Type 2 diabetes. It is also important to equip trainees with skills that are aligned with their career goals whilst meeting the population's needs. It is necessary that professionals already in the workforce are updated on current evidence-based practice guidelines and offered courses and/or training to bridge the existing gaps in skills and competencies. Continuous professional development training needs to be offered to meet the needs of the community, especially for those who do not have access to

rehabilitation services, and incentives should be offered to pursue advanced courses and develop skills in specialty areas. The COVID-19 pandemic has proven that distance and online learning options are feasible. This could be an option to support capacity-building of rehabilitation professionals.

2.2. Strengthen healthcare systems at all levels (sub-, primary-, and community-health centres) to offer rehabilitation services that cater to the needs of local communities. As rehabilitation services are concentrated in urban areas, there is a need to build the capacity of the other professionals to offer basic rehabilitation services at various levels of the healthcare system.

2.3. Curriculum development: Developing a uniform physiotherapy training curriculum of similar duration across all educational institutions. There should be a core programme while allowing flexibility to incorporate the context-specific needs of the local population which the trainees will serve in the future.

2.4. Job descriptions: Clear job differentiation and salary scales should be in place among rehabilitation professionals with Bachelor's, Master's, and Doctoral degrees. Some specialised activities could be reserved or legally controlled. In other words, to be able to perform some interventions, physiotherapists must seek additional certification or obtain higher qualifications.

3. Research capacity and training: Research activities in rehabilitation are still underrated and limited to work done at academic institutions. Several factors that could impact the quality of research are the limited or lack of dedicated funding to support rehabilitation research, non- acknowledgment from peers in the medical community, and limited access to published materials due to expensive paywalls. This however is changing, thanks to open access policies and open science frameworks adopted by some institutions in higher-income countries. The Lancet journal, for instance, has shown a commitment to starting region-specific open access to scientific publications. There is a need to develop research capacity and collaborate with the international faculties in knowledge sharing and writing publications. Citations and cross-references are increasing from journals in Asian countries.

4. Population outlook towards rehabilitation: Increase awareness and health literacy among the public towards seeking rehabilitation services, not only for return to function following acute injuries but also for health promotion, physical activity, self-management, and to meet their goals in living a

healthier life. This will require information sharing among various healthcare professionals, and referrals to and from rehabilitation services. Rehabilitation professionals have to be called upon for their role as 'advocates and leaders' for accessible and sustainable services across and beyond the continuum of care.

5. Community programmes: One way to meet the needs of the community is to develop and support sustainable implementation of evidence-based community programmes. This will require the engagement of stakeholders such as community leaders, rehabilitation professionals, and local government. Programmes such as these need funds allocated by the Central and/or State Governments and, where possible, charities and philanthropies could supplement their efforts.

6. Developing and supporting innovations and entrepreneurship in rehabilitation: According to the World Confederation for Physical Therapy (WCPT), there are totally 48,396 physiotherapists in India, which is the equivalent of 4 physiotherapists for every 100,000 people. This is in contrast to the numbers seen in other countries for every 100,000 people, 68 physiotherapists in Canada, 76 in Australia, 74 in the United Kingdom, and 20 in the USA. The small number of physiotherapists in India will not be able to meet the rehabilitation needs of the large socio-culturally diverse and geographically dispersed population. Approximately, 29.2% of men and 32.6% of women over the age of 65 years reside in rural India (Mishra, 2020) with little or no access to rehabilitation services. Technology will increasingly play a key role in meeting demands and in reaching inaccessible populations in remote regions. Now that internet and the mobile phone have reached every corner of India, the next step would be to support innovation and technology to bring rehabilitation services to people. Several free health apps and online programmes are already on the market. For instance, RehApp is a free mobile app developed to support fieldworkers in low- and middle-income countries while engaging with people with disabilities (https://enablement.eu). Due to the COVID-19 pandemic, some of the innovations were employed in remote monitoring, telehealth, and online consultation to track and monitor people with coronavirus infection. These measures could be harnessed by the rehabilitation community to provide services to hard-to-reach populations in rural areas.

7. System-related issues: Currently, unlike most rehabilitation professionals, physiotherapists are not covered by the Rehabilitation Council of India. There

is a national regulatory body, the Indian Association of Physiotherapists (IAP), that maintains some information on membership and training institutions, and several States have created their own regulatory boards to maintain membership records. However, the lack of a central regulatory authority impedes participation in international initiatives such as the WCPT. The IAP was allowed to rejoin the WCPT in 2020, after a long wait. There is an urgent need to establish a national regulatory authority that has the power to monitor, inspect, certify, and maintain acceptable quality of memberships through mandatory formal and informal training, and standardise practices across different specialties.

Bridging the gap between the population needs and the existing rehabilitation services is the first step towards developing a comprehensive plan to overcome existing challenges. While some of these challenges can be addressed immediately, others would require a long-term commitment from different stakeholders.

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Kedar K. V. Mate[1], Dipti Geete[2]

1. Director, Health Outcomes Research, Centre for Neurological Restoration, Cleveland Clinic, Ohio, USA.

2. Assistant Professor, Department of Physiotherapy, Seth G S Medical College and KEM Hospital, India

* **Corresponding Author:** Kedar K. V. Mate, Post-Doctoral Fellow, Centre for Outcomes Research and Evaluation, McGill University Health Centre Research Institute, Canada. Email: kedar.mate@mail.mcgill.ca

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