



DISABILITY, CBR & INCLUSIVE DEVELOPMENT

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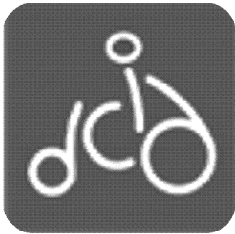
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Editorial: The Land of Unequal Opportunities...

Once upon a time a tortoise and a hare had an argument about who was faster. They decided to settle the argument with a race. They agreed on a route and started off the race. The hare shot ahead and ran briskly for some time. Then seeing that he was far ahead of the tortoise, he thought he'd sit under a tree for some time and relax before continuing the race. He sat under the tree and soon fell asleep. The tortoise plodding on overtook him and soon finished the race, emerging as the undisputed champ. The hare woke up and realised that he'd lost the race. The moral of the story is that the steady and determined one wins the race.

Today's version of this narrative would introduce several new elements: there would have to be a judge; there would have to be prizes, first as well as second and certainly, there would be a book of rules. And the book of rules would make the judge's decision final; it would not, in fact, provide for hares and tortoises to race together; and the highest award would be reserved for the swift, while the admirable tortoise would receive scant consolation.

Now in the language of fables are written some of the first philosophic certainties of men. The fable makes use of a simple animal alphabet to spell out the plainest truths. In the tale I have recounted, we discover in the hare the insolence of superiority. The foolish hare, presuming upon his natural talents and having the utmost contempt for his adversary, loses the race through over-security. On the other hand, in the constant even pace of the tortoise is found the benefit of patience and diligence.

That perseverance can triumph over natural advantage is the moral of the story. I am convinced that, in the life of a person with a disability, no single quality, no trait necessary to overcome difficulties, is of greater importance than perseverance.

I first heard the above fable and lessons for the world in which we live – the land of unequal opportunities – in the mid-eighties of the last century during a powerful speech of by Dr William Rowland during the national (South African) year of the disabled, as it was called then. I hope that the young(er) readers of this journal will forgive me for sharing this old story, because it has a purpose. Forty years later, I am increasingly asking myself if the world has changed and especially if the world has become a better place. And yes, I admit and have to admit that the world has changed – and in many ways has become a better place

for many people including many people with disabilities. Watch the exciting TED sessions of the late Dr Hans Rosling and you will realise that on many fronts the world has become a better place. Something we tend to easily forget when we live in our own 'bubble' in affluent and democratic societies where the rights paradigm becomes a façade at times for spoiled individuals who always want more and who are never satisfied. The great improvements in public health, education, economic development may not be seen however, by those living in low-and middle-income countries and in countries where one doesn't dare to refer to 'rights'. This in particular could be the case for those who continue to live in poverty or those who are continually being stigmatised and excluded from mainstream developments.

Most articles that are published in this journal refer to the lives of people with disabilities and their families who live in low-and middle-income countries and in countries where people suffer under dictatorship. I hope that everyone who is reading and contributing to this journal realises this. If you do, you may increasingly start appreciating the fact that many of the contributors write because they have a mission. They cannot sit still but want to share the often small but valuable contributions which should lead to a better and more inclusive society with you and me. I therefore would like to thank all those who contribute their research studies, experiences and at time reflections with you and me. This journal would not exist if people were not taking the time to – at times meticulously – study important subjects, write down results of studies being done and hope that their work will contribute to new insights, better practices and if lucky, even new policies and developments. I also would like to thank all those reviewers who critically review articles (and some have done so for years); provide – critical – feedback but all to ensure that the quality of manuscripts will improve; flaws in studies be identified; and offer valuable suggestions to authors. These reviewers do this for free; they don't get a penny for it nor do they get formal and public acknowledgment for the excellent work they are doing on a voluntary basis. Without them this journal would not be there! I am calling upon you and especially the experienced readers and authors to register yourself as reviewer; something which simply can be done at the homepage of www.dcidj.org

As editor-in-chief I wish to challenge you, however, beyond the question of becoming a reviewer. I want to request you to write and submit articles that lead to debate. We cannot permit ourselves to be satisfied with high(er) impact rates of

the journal as long as the lessons from your publications are not being debated or in fact are not leading to a debate that will influence decision- and policymakers. There is a dearth of - at times excellent - quality of articles being published but I am concerned about its application in the field. The DCID journal is not meant to be a journal for academics per se but the fact that the journal is supported with public funds means that we have a responsibility and an obligation to make sure that the journal is meaningful to society and its transformation into a society that is more egalitarian and inclusive of all. During the coming months, discussions will take place with various editorial board members about the future of the journal. We will discuss at first in a small group ideas and ways to make the above become reality and we obviously will involve you as readers and contributors in these developments as well. In the meantime, I will invite you to write to me and share your ideas and concerns.

Wishing you well in your work and stay healthy in these challenging times of Covid-19!

Huib Cornielje
Editor-in-Chief
DCID Journal

Scaling of Organisations of Persons with Disabilities: A Case Study in the People's Democratic Republic of Lao

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ABSTRACT

Purpose: *The ability to have impact at scale is an important concern for Organisations of Persons with Disabilities (OPDs), but little is known about how scaling occurs in practice and the capacity of OPDs to undertake scaling. The aim of this study was to assess perceptions and experiences of scaling and broader organisational practices among a sample of people working for OPDs in Lao PDR. The study also aimed to deductively analyse the qualitative data in relation to a pre-defined socially inclusive scaling framework.*

Methods: *In-depth interviews were conducted with a sample of people working with 10 OPDs operating in Lao PDR (n = 12; 6 female and 6 male). Participants included directors, administration personnel, and advisers of OPDs. Grounded theory was used to analyse the qualitative data. A deductive approach, comprising a multiple cycling coding process, was used to analyse the data in relation to the IPILA socially inclusive scaling framework.*

Results: *Participants reported their perceptions of scaling and broader organisational practices in relation to eight themes: OPDs' relationship with government; collaboration among OPDs; legal registration; operational challenges; good practices for success; different strategies across OPDs; next steps to improve the work of OPDs; and implementation of policies. Findings from the deductive analyses indicated that OPDs use different strategies to include their members and/or service-users. The OPDs scaled in different directions, despite facing operational challenges such as funding and technical expertise. While OPDs identified scaling practices, they react to rather than plan scaling opportunities.*

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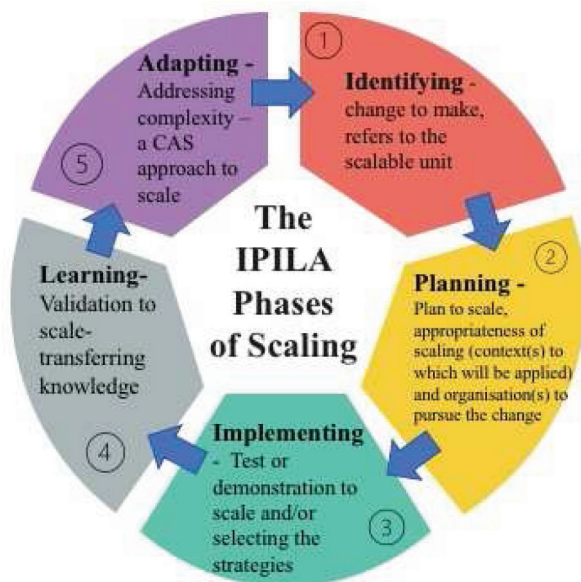
Conclusion: *This study addressed the ways in which scaling is understood by OPDs in the context of Lao PDR. The findings show that OPDs recognise their good practices and the steps needed to scale, but lack planning and monitoring processes for scaling.*

Key words: *Organisations of Persons with Disabilities (OPDs), social inclusion, scaling, good practices, Lao PDR*

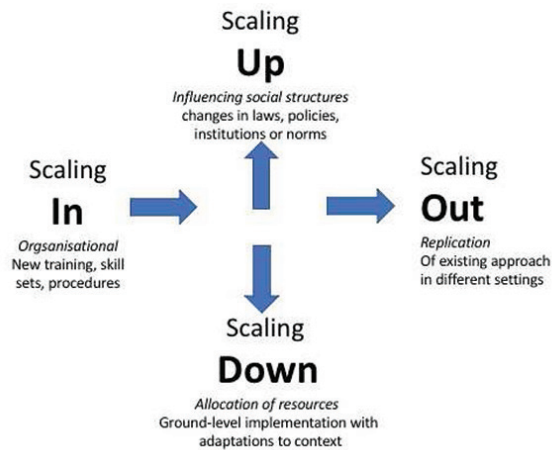
INTRODUCTION

Organisations of Persons with Disabilities (OPDs) aim to implement and innovate good practices to fulfil the rights of persons with disabilities, and in so doing to promote their social inclusion. There are currently more than 20 different frameworks to guide scaling, which have recently been synthesised into an approach that is focused on social inclusion, and is therefore very relevant to challenges that face OPDs (Sánchez Rodríguez et al., 2020). Scaling often requires dissemination of ideas, transfer of methods, and improving the quality of interventions to increase the scale of impact (Binswanger & Aiyar, 2003; Hancock et al., 2003; Manor, 2007; Hartmann & Linn, 2008), and “doing it more reliably, more efficiently, and with a steady improvement in quality” (Seelos & Mair, 2016). In this paper, scaling is considered to be influencing, repeating, adapting, and ensuring social change for vulnerable populations, and in particular for persons with disabilities. Scaling for social change requires targeting harmful social norms, such as those that reinforce discrimination against persons with disabilities (Carter et al., 2018). Multiple forms of discrimination coexist within complex systems. Therefore, changing these systems often follows successive approximations or “the amplification of micro-level interactions” (Burns & Worsley, 2015) to produce macro-level changes in the settings and conditions in which people live (MacLachlan & McVeigh, 2021).

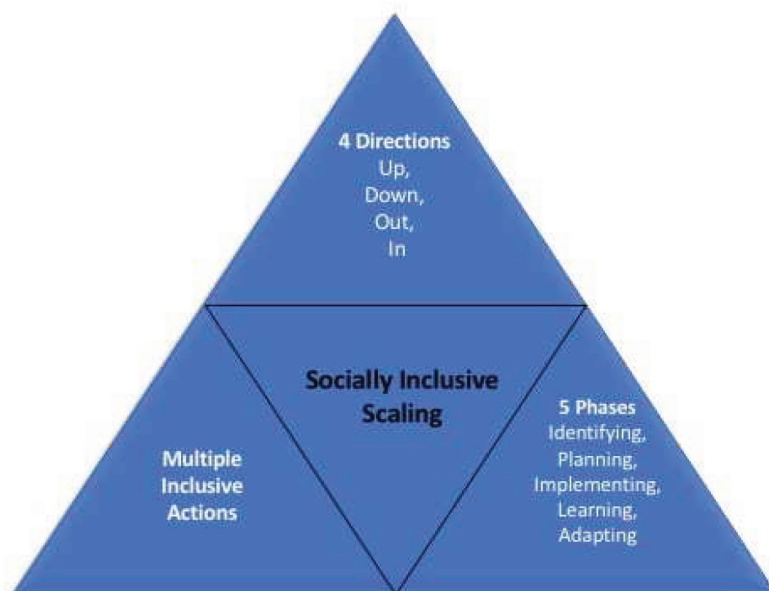
While there are multiple approaches to scaling, there are typically five phases in terms of process: identifying, planning, implementing, learning, and adapting - IPILA (Sánchez Rodríguez et al., 2020). More specifically, these phases include: 1) identifying an intervention (e.g. innovation, good practice, project, programme, and policy) (Jonasova & Cooke, 2012); 2) planning based on evidence-based good practice; 3) implementing the scaling plan using different strategies, depending on the scaling direction adopted (Weber et al., 2012); 4) learning and knowledge transfer (Taylor & Taylor, 2016); and 5) adapting to uncertainty and unpredictability (Sánchez Rodríguez et al., 2020). These five phases are schematically presented in Figure 1.



Scaling can also be distinguished in terms of directions. Four scaling directions were emergent from Sánchez Rodríguez et al.'s (2020) review and synthesis of the literature – ‘scaling up’, ‘scaling down’, ‘scaling out’, and ‘scaling in’ – with each direction having its own strategies and goals (see Figure 2). The ‘scaling up’ direction focuses on structural changes at institutional levels. In the ‘scaling up’ direction, the organisation implements strategies such as negotiating with policy-makers or building strong networks with stakeholders in order to advocate. The second direction is ‘scaling out’, where the organisation strives to broaden its scope geographically. ‘Scaling out’ implies replication by communicating and diffusing the practice. A third direction is ‘scaling in’, and its goal is to pursue change within the organisation. For example, this might be achieved by adding a component that contributes to the organisation’s overall objective, giving it improved capacity to deliver on its mission. Finally, the ‘scaling down’ direction requires a better understanding of the needs of community-based organisations and devolving resources to reach out to communities.



While Sánchez Rodríguez et al. (2020) identified five phases for process and four directions for scaling, the inclusion of marginalised groups may be strengthened by following a number of complementary steps. First, an inclusive intervention must be identified, signifying “the development and implementation of new ideas (referring to innovation) which aspire to create opportunities that enhance social and economic well-being for disenfranchised members of society” (George et al., 2012), promoted through organisations whose main purposes are social (Mulgan, 2006). Second, activities must be planned and initiated with the community. Third, community participation can be reinforced in the process of change. Fourth, organisational learning must be incorporated that includes the ideas, perceptions, and opinions of the community. Finally, inclusive ideas, practices, or projects can be adapted to reflect the views of marginalised individuals or groups. These five steps can promote socially inclusive scaling to strengthen the ownership of OPDs. Analysing and understanding the context in which OPDs’ interventions are implemented is also recommended. This framework for socially inclusive scaling is presented in Figure 3.



Lao PDR as a Case Study

Lao PDR, founded in 1975, is a low-income country, bordering Cambodia, China, Myanmar, Thailand, and Vietnam (FAO et al., 2016). The country is divided into 18 provinces, with Vientiane as the capital city situated in the south (Lao Statistics Bureau, 2016). The country has a population of 7.1 million people including 50 ethnic groups, with two-thirds of citizens residing in rural areas (UN Lao PDR, 2019). According to the 2015 Population and Housing Census, disability prevalence is higher in rural areas – 2.5% in urban areas, 2.9% in rural areas with roads, and 3.3% in rural areas without roads (Lao Statistics Bureau, 2016). The most prevalent forms of disabilities include impairments related to seeing (1.3%) and walking or climbing stairs (1.3%), followed by hearing (1.2%), remembering or concentrating (1.2%), self-care (1.1%), and communicating (0.9%) (Lao Statistics Bureau, 2016). Disability is frequently stigmatised in the country (Thoresen et al., 2017) and viewed as bad luck. In some cases, families prioritise the needs of their healthier members with no disability (Buchner, 2011).

While the country has assented to several principal international human rights treaties, a key challenge is reducing inequities amongst marginalised groups. As proposed by the FAO et al. (2016):

“One of the main development challenges is ensuring that the benefits from high economic growth, averaging more than 7 percent Gross Domestic Product (GDP) for the past five years, are evenly distributed and translated into inclusive and sustainable human development. Widening gaps between rich and poor, women and men, ethnic groups, and residents of different regions of the country need to be addressed”.

Lao PDR was selected as a case study due to recent developments in the country towards the inclusion of marginalised groups, particularly persons with disabilities, including the expansion of OPDs. Lao PDR’s first focus on disabilities was on casualties due to unexploded ordnance (UXO) from bombs dropped during the US-Vietnam war. The UXO caused 13,500 people to have disabilities between 1964 and 2008, and it continues to have an impact in the Lao population, claiming new victims even today (Committee on the Rights of Persons with Disabilities, 2017).

The Lao government has made progress in recognising the rights of persons with disabilities. In 2009, the government signed and ratified the Convention on the Rights of Persons with Disabilities (CRPD). The first Lao PDR initial report to the CRPD Committee also highlights the emergence of non-governmental organisations as a strategy to advance the rights of persons with disabilities (Committee on the Rights of Persons with Disabilities, 2017). Furthermore, the National Committee for Disabled People and the Elderly (NCDE) presented a Disability National Law that was enacted in 2019 by the General Assembly of Lao PDR, which specified the role of OPDs.

The first OPDs in Lao PDR began working in the late 1990s and early 2000s. However, it was not until 2009 that OPDs were officially recognised by the State under Decree no. 115 on Associations (Lao PDR Ministry of Industry and Commerce, 2009). The Decree no.115 was replaced in 2017 by the Decree no. 238 on Associations, which defined in Article 11 “social welfare and development associations” including those working with persons with disabilities (Lao PDR Ministry of Home Affairs, 2017). OPDs in the country are diverse in their scope, focus, and structure. They include parent-driven associations such as the Association for Autism (AfA) and the Intellectual Disability Association (IDA), and OPDs funded by groups of persons with a specific disability such as the Vocational Development for Blind Association (VDBA) and the Association for the Deaf (AFD). OPDs have registered with the Ministry of Home Affairs, enjoying more freedom to apply directly for funds and participate in government

meetings (Lao PDR Ministry of Home Affairs, 2017; Article 20). The AFD and the IDA (formerly known as the Intellectual Disability Unit) were sponsored by the Lao Disabled People's Association (LDPA) to legally represent them. The Intellectual Disability Unit obtained its registration and in 2019 became the Intellectual Disability Association, no longer needing representation by the LDPA. While the LDPA has traditionally been considered an umbrella organisation, each organisation is independent and participates equally in the network. Appendix A provides a description of OPDs in LAO PDR, including the year that they were founded and/or registered, number of members/beneficiaries, area of influence, targeted disability population, and areas of work.

Most of the OPDs are based in the capital, Vientiane, with the exception of the AfA, LDPA, and the Quality of Life Association (QLA), which operate in other provinces. The national government's role for persons with disabilities has been limited and inconsistent, with OPDs implementing most initiatives for persons with disabilities such as rights promotion, income generation, and inclusive education. For example, OPDs organise teacher training for inclusive education, implement income generation activities such as cattle raising, provide transportation and promote sporting activities for persons with disabilities. Indeed, OPDs' good practices have been highlighted in projects by international non-governmental organisations to support OPDs, such as the "Sharing of Good Practices/Lessons Learnt" workshop organised in December 2018 with the support of Humanity and Inclusion (HI). In this workshop, the following good practices of OPDs were presented: the AfA's Lao Autism Talk app, developed with the support of a tech company; the Lao Blind Association's (LBA) and the VDBA's practice of registering blind students at the National University of Lao; and the QLA project to ensure access to primary and secondary school for persons with disabilities in Xieng Khouang Province. These good practices were recognised due to their potential to scale, in terms of increasing impact and accessing remote areas (Wardle & Phandanouvong, 2018).

Objective

The ability to have impact at scale is an important concern for OPDs. However, little is known about how scaling occurs in practice and the capacity of OPDs to undertake scaling. Previous literature focuses on the scaling of non-governmental organisations, without differentiating OPDs from other organisations, particularly in low- and middle-income countries (Guha, 2019).

In response to this gap in the literature, the aim of this study was to assess perceptions and experiences of scaling and broader organisational practices amongst a sample of people working for OPDs in Lao PDR. This study also aimed to deductively analyse the qualitative data in relation to the socially inclusive scaling framework outlined above. Using Lao PDR as a case study, we explored whether OPDs were scaling their practices and, if so, how scaling was signalled, by examining the scaling phases and the directions that OPDs might be taking.

METHOD

Setting

This study is part of a larger qualitative study conducted in Lao PDR from 2018 to 2019, in collaboration with HI.

Study Sample

Purposeful sampling was used to recruit a range of OPDs in Lao PDR. These OPDs were identified with the support of HI, who had been working with them to strengthen their practices. In-depth interviews were conducted with a sample of people working with 10 OPDs operating in the country ($n = 12$) (6 female and 6 male). Participants included directors, administration personnel, and advisers of OPDs.

Data Collection

In total, 16 interviews were conducted, with two participants present in three of the interviews. Eleven interviews were conducted in March 2018. Five follow-up interviews were subsequently conducted between November and December 2019, with OPDs that had reported scaling in the first interview. Three of these follow-up interviews were with the same participant.

Interviews were conducted at the venues of OPDs. While 13 interviews were recorded, 3 interviews were not, as participants did not consent to being recorded. Eight interviews were conducted in Lao language, using consecutive interpretation from Lao to English, and availing of a sign language interpreter when required. The field researcher recorded notes in a field notes diary, writing direct observations immediately after interviews to describe any additional information that was observed and interpreted (Deggs & Hernandez, 2018).

Study Tools

The primary researcher designed a 7-item interview schedule, which focused on general information about the interviewee and organisation, the organisation's relationships and networking, areas of expertise, practice presented and selected by HI-Making it Work, good practices, and scaling up. The interview guide focused on 'scaling up' as a general overarching term for all four scaling directions. The interview schedule is provided in Appendix B.

In addition to the in-depth interviews, a workshop was organised in May 2019 with 13 OPDs. The purpose of the workshop was to analyse the OPDs' good practices and to understand perceptions and experiences of scaling. The socially inclusive scaling framework was refined after the interviews were conducted, and the revised framework was presented at the workshop. The framework was also iteratively revised after the workshop. The workshop plan is provided in Appendix C. Scaling was translated and understood by respondents as improvement and expansion (*kanpabpung* and *kankhajaitua* – the Lao words to refer to improvement and expansion). The terminology that OPDs used to refer to scaling was developed further in the workshop, and included the concepts of improving, growing, continuing, planning, practicing, creating, and expanding.

Data Analyses

The primary researcher transcribed the data in full. Grounded theory was used to analyse the data (Glaser & Strauss, 2017). A deductive approach, comprising a multiple cycling coding process (Rossman & Rallis, 2012), was also used to analyse the data in relation to the IPILA socially inclusive scaling framework outlined above. In the first cycle, open coding was used to first analyse the content that emerged from the data. The second coding cycle rearranged the information by identifying codes related to the scaling phases described above. In the third and last cycle, sub-codes were created for strategies that pointed to each of the phases, and coding was applied through the lens of the five steps of a socially inclusive scaling approach, as outlined above.

Several mechanisms were used to strengthen the validity of the study. Data were collected from different sources for the purpose of data triangulation (Miles et al., 2020). For example, data from the field notes diary were used to provide information on the contextual settings of interviews. Member-checks were also conducted across OPDs, in collaboration with HI and Maynooth University advisors. Furthermore, follow-up interviews were conducted to examine the

accuracy of data, and to provide further clarification of information with HI Lao (Maxwell, 2013). Finally, the design of this qualitative research study required an immersion in the organisational environments of the OPDs at two time points, to explore the organisations, their context, and cultural nuances and differences amongst them and with their partner organisations (Ragin & Amoroso, 2011).

Ethical Considerations

Ethical approval for this study was granted by the Maynooth University Social Research Ethics Subcommittee.

RESULTS

Emergent Themes

This section presents findings from the inductive analyses of the data using grounded theory. Participants reported their perceptions and experiences of scaling and broader organisational practices in relation to eight themes: OPDs' relationship with government; collaboration amongst OPDs; legal registration; operational challenges; good practices for success; different strategies across OPDs; next steps to improve the work of OPDs; and implementation of policies. Each of these themes is discussed in more detail below.

OPDs' Relationship with Government

Participants emphasised the importance of their relationship with government. All participants reported some form of collaboration with government, indicating that all 10 OPDs had a relationship with a government entity at the national or provincial level. For example, one participant communicated the need for OPD collaboration with the government, as follows:

"I think we have been working closely with the Ministry of Education to make inclusive education happen, to get them to agree to accept our children in primary school, secondary school. It is not really a big policy change because our government already has good policy right, but I think more than making more policy, it is putting into practice there we are not changing anything" (P10).

Participants reported that OPDs' relationships with government were important, but sometimes challenging. For example, one participant communicated:

“So it is not easy as you know, especially for the government, especially for the ministry, to understand. So what we had to do is we had to do a lot of heavy work on advocacy” (P3).

Two participants mentioned the need to report to the government, and one participant mentioned the need to inform the government before receiving funding. As one participant remarked:

“Of course what we did, meaning the government, how do I say that we had monthly, yearly, report for the government as Ministry of Affairs and about whatever because we are under government legality, so whenever we have a programme or activity we need to inform them to know what we do, so that is why we have annual report for yearly, and we report for the government and ask permission every time of what we do” (P4).

Collaboration among OPDs

Participants reported that OPDs work together and meet quarterly. They asserted that collaboration among OPDs was important to amplify their voices. Two participants specifically mentioned the OPDs’ network as a space for OPD collaboration. One participant stated:

“... but are not doing it ourselves alone you know. I think we also team up with other disability organisations so that the voice is louder, and we don’t want to sort of, you know, do it alone” (P10).

Participants reported that OPDs exchange information and participate in activities organised by the group or independently. One participant commented:

“When we are making audio books or computer tutorials or something else, we have some meeting, and we invite OPDs to share ideas or to come with something else for our projects; and we have some good comments. We have a good network, we share how you say, when they have some organisations to call for funding, we join together sometimes” (P1).

The participants detailed how they participated in the activities of other OPDs. One participant explained:

“Always participating in other meetings with other OPDs every three months.... for example, if they have some activities, even other OPD has its own activities for example, some activities about the types of disabilities, the AFD will be

participating and also contributing in their role promoting their organisation with other OPDs” (P2).

Notably, one participant mentioned the support of HI to strengthen the network of OPDs:

“So our relationship is regularly exchanging information, especially in the quarterly meeting. This meeting is actually funded by HI and strengthens networking of OPDs; and in these meetings, we will discuss our own work in each organisation and also the plan of each organisation and the issues the organisation faces, and find ways to help one another” (P7).

Legal Registration

Participants reported that the OPDs were established before they were legally registered. However, the IDA, for example, was not registered at the time of the interviews, and the AFD has not achieved registration to date. Registration allows the organisations to be formally recognised by the State. As explained by two participants, registration also requires OPDs to periodically report their activities to the Ministry of Home Affairs. One participant asserted that the legal registration process was arduous, but important to achieve:

“So it was a long process that they stuck with, and now they are one of the few organisations that are registered and can tick one of the boxes, so that’s a huge in policy a good example for civil society of how to work with government by being registered” (P9).

Operational Challenges

OPDs articulated multiple challenges in their work. The most common challenges were lack of technical and management expertise, alongside funding. However, participants reported other challenges such as lack of communication, awareness, their own space, expertise of their counterparts, and adequate materials. Eleven participants highlighted funding as a challenge, as exemplified by one participant’s observation:

“We have to find a way to survive as an organisation, so it is a lot of effort to try to find money working with government, with donor government, to identify projects, to find a match in our interests and needs, and have the money to support our activities” (P10).

In relation to the challenges of funding and technical expertise, another participant emphasised:

“For the advocacy work he said that we wish to expand, but there are still so many challenges because most of this success of the advocacy work is based or under the project life span; and when the project finishes, everything stops. For example, we don’t have enough funding or budget to run the project any more, and the person who used to be part of the advocacy is not there anymore, because we need more like a qualified person and that person has to be skilful and they have to know law and they have to know the legislation, a lot of things. They have to know everything in detail, but unfortunately we don’t have that person anymore, and that’s the challenge they have now in expanding their advocacy work” (P7).

Good Practices for Success

All of the participants could identify good practices in their OPD. One participant asserted that their OPD’s good practices were recognised and had received an international award. Participants reported the following elements of success: government support of initiatives, accessibility to users, international recognition, and offering economic activities for self-employment to persons with disabilities. For example, in relation to good accessibility practices, one participant specified:

“So the reason why she chose this good practice is because everyone can access this application, even people who are far away from this training centre, and they don’t have to travel here; and everyone can learn about this because it is a video demonstration” (P7).

Another participant commented on providing economic activities for self-employment to persons with disabilities:

“Because these activities are more like a living style of people, the way of living, especially the vulnerable people with disabilities, even the income is low, but still is good enough for them, and also cheers them up that they still have some income source” (P5).

Different Strategies across OPDs

Participants indicated that their practices and strategies were diverse. They reported, however, that common strategies across OPDs included: awareness

of the community, awareness of contextual differences, engagement with stakeholders, transferring skills, adapting new organisational models, developing an organisational model with the participation of members, adapting the model according to the needs of the group, and acknowledging and addressing specific needs. For example, one participant emphasised the importance of taking context into consideration:

“Every province has its own unique thing, and I don’t want to sort of copy what we have in Vientiane everywhere. It has to fit the local context” (P10).

Another participant discussed the development of an organisational model with the participation of OPD members:

“My strategies or my solution because every week we have like a good connection, like a discussion, like each unit they have their own plan, then we have a meeting, then we consider together. So for my idea I want to give independence to kind of disability under the same rules, you understand what I mean, we need to have independence because I am not the boss, I am just a leader, but you must become a leader and lead your team. That is my idea” (P12).

One participant emphasised the importance of acknowledging specific needs and addressing them by asking service-users first:

“We discussed the first steps after we asked that person and family. We need to ask that person. We ask, ‘what do you need and how can we help you?’” (P8).

Next Steps to Improve the Work of OPDs

All participants outlined steps to improve their work. Ten participants, across nine OPDs, mentioned plans to expand their OPD. For instance, one participant reported:

“We are in an expanding phase ... I believe to be in a successful expansion we need to be at core a core team” (P10).

Similarly, another participant asserted:

“Of course, we are trying to grow up and what is our motto? ‘Nothing about us without us.’ I am trying to promote the young generation of all kinds of disabilities to respond to their own disability; we are trying to establish like a unit” (P12).

One participant referred to fundraising and advocacy to attract donors and other organisations to invest in the OPD's programmes:

"First thing you have to do is to do a fundraising first to interest donors and organisations. What we have to do is a lot of advocacy to attract their attention to invest in our programmes" (P3).

Implementation of Policies

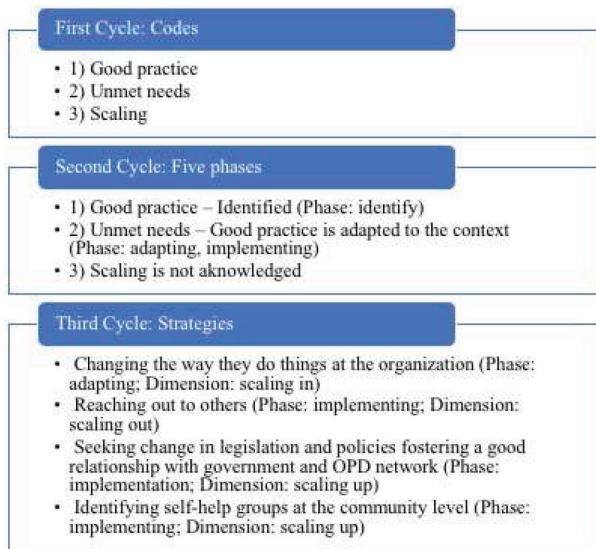
Three participants stated that policies had been developed for persons with disabilities in Lao PDR, but were not fully implemented. As one participant suggested:

"...in Lao, we have a lot of things, very nice legislation and policy, but not really implementing" (P12).

Two participants discussed the development of a policy framework on inclusive education, which had not been implemented. One participant asserted that national policies did not focus on persons with intellectual disabilities.

Socially Inclusive Scaling Framework

This section presents findings from the deductive multiple cycling coding process used to analyse the data in relation to the socially inclusive scaling framework. Figure 4 presents general themes that emerged from the three stages of the cycling coding process.



Participants selected and highlighted the successes of their work. None of the participants reported having scaled as such, and yet all addressed interventions and innovations that had been expanded or replicated in some way. OPDs are not necessarily pursuing scaling in a systematic way, for instance using all the five phases in the process. This is particularly so in the planning phase. New activities result more from seizing an opportunity, such as new funding or support from interest groups. The study findings are summarised in Table 2.

Table 2: Socially Inclusive Scaling Framework and Findings from Interviews

Scaling Phase	Definition of the Phase in Socially Inclusive Scaling	Findings from Interviews	Examples	Participant Quotes
Identify an inclusive practice.	Identifying the intervention, and with it the scaling direction that the organisation will pursue. In socially inclusive scaling, the focus is on how the intervention is creating changes and opportunities for persons with disabilities.	<p>1) There is no confusion or hesitation in identifying their own good practice, provided that there is internal and external recognition of the practice.</p> <p>2) There is no overlapping of good practices/interventions amongst organisations. Each organisation is focusing on their own practice, and their practice is unique for their service-users.</p> <p>3) Interventions are fit to purpose and to the target population. Moreover, <i>good practices</i> refer to successful interventions that are accessible to the population they serve.</p>	<p>1) External recognition and awards by national and international organisations (e.g., AfA, AFD). Internal recognition of single or multiple successful practices, such as the Disability Rights Empowerment Training (DRET).</p> <p>2) AFD practices include “Hand Me” and “Hand Talk”, which are a series of videos on Lao sign language for people with hearing impairments. AfA has the Lao Autism Talk app, which is focused on the needs of persons with autism and intellectual disability.</p> <p>3) AFD mentions that the app is relatively easy to use and accessible for all people.</p>	<p>“We won three awards. We won ICT award when we launched; and then the Ministry of Communication sent our app to ASEAN, so we won the civil award under the social corporate responsibility. You know, they have different categories, 6 categories. We won the second award of the social corporate responsibility because of the impact of the app...” (AfA director, personal communication, March 2018).</p>
Planning scaling.	The scaling planning process requires an analysis of what is feasible and collecting evidence of what has worked, including steps and strategies. In socially inclusive scaling, the planning process and plan is built and shared with the communities.	<p>1) No planning or limited planning according to the resources available. This phase overlaps with adapting.</p> <p>2) The OPDs do not have a formal planning process to scale and a written scaling plan. However, all of the OPDs are cognisant of the next steps to scale. AfA is the only OPD that addressed scaling in its strategic plan structure.</p>	<p>1) AfA’s app works on an Android system. A second phase was planned to develop the app for an IOS system, but the OPD did not have the necessary funds.</p> <p>2) AFD is calling for the government to provide sign interpreters at all public events. AfA is advocating for the State to provide teacher training and to introduce inclusive education in all schools, not only in the Vientiane capital. AfA’s Strategic Plan 2012–2020 highlights the expansion of their education centre.</p>	<p>“So in the future as today, she is planning to expand the community of the sign language, especially to rural areas and also to other provinces, and also do some [inaudible] working in schools and other organisations, even inside the country and outside the country, and also building a networking through the countries” (AFD director, personal communication, March 2018).</p>

		3) Planning takes place collectively at the OPDs' network meetings, including planning to scale up to influence change.	3) Sharing planning with the OPD network to support their actions and joint efforts to obtain funding.	
Implement actions to scale.	Resource mobilisation and the organisation investing for scaling. Socially inclusive scaling will comprise design feedback mechanisms that are sensitive to and capable of reinforcing community participation.	<p>1) A <i>gradual approach</i> to scaling, according to the opportunities that arise (the momentum), e.g., funding opportunities or by request from interest groups.</p> <p>2) OPDs stated that they received feedback from their service-users.</p> <p>3) OPDs simultaneously plan and implement scaling. Implementing scaling is a spontaneous process; it is not pre-planned (Edwards & Hulme, 1992; Hartmann & Linn, 2007). However, this stage implies using a variety of strategies.</p>	<p>1) AfA expanded to Pakse (scaling out), initially by request of a group of parents. LBA first approached the Ministry of Education to include blind students at the National University of Lao.</p> <p>2) LBA getting feedback from the blind students at the National University of Lao and AfA from the users of the Lao Autism Talk.</p> <p>3) AFD, for example, expressed interest to expand their actions by approaching rural communities.</p>	<i>"Hasn't been a formal branch yet, so we found a group of parents. We cannot set up the centre because this group of parents can't pay the fee, so we need at least ten parents who can pay the fee to set up the centre, so these parents can't, so we can't set up the centre; but we are planning to engage parents to get to know one another more and maybe having a group session maybe once a month to sort of get to know one another, to have an activity together. We don't have to have a centre, but get the activity going, so I want I am aiming to work with the father leader" (AfA director, personal communication, November 2018).</i>
Learning lessons.	Knowledge transfer-related scaling from the organisation. In socially inclusive scaling, the learning phase is a space to reflect without stopping implementation and should overlap with it.	<p>1) Learning has led some of the OPDs to scale out – there are limited examples of other types of scaling. OPDs that have replicated in some way have adapted their intervention.</p> <p>2) OPDs' feedback processes are not formalised. In most cases, feedback processes are confined to external evaluations when there is international funding. However, OPDs are required to provide regular reports to the government, but it is unclear if this leads to an analysis of lessons learnt.</p> <p>3) Feedback is obtained by comparing other experiences elsewhere. OPDs are learning from counterparts in other countries.</p>	<p>1) AfA pays attention to strengthening the organisation and explains to their staff what is expected of them (defining people's roles at the central and provincial levels).</p> <p>2) A rare example of OPDs' evaluation processes is QLA, which has a mid-term or quarterly evaluation depending on the nature of the project, to make necessary changes to improve the project. However, this is a regular practice, not necessarily in the context of scaling.</p> <p>(3) LBA has exchanges with Thailand counterparts that come to Lao PDR to train staff in the National University of Lao on the use of assistive products, such as voice programmes for students who are blind.</p>	<i>"The plan is not to expand, but to update what we have now first, because the programme itself has not functioned 100% yet. It is not 100% like English voice programme; but now we are working with Thailand, the people in Thailand, to help us to update the programmes to become 100% functional" (President of LBA, personal communication, March 2018).</i>

Adapting practices.	Linked to the learning process, adapting aims to address complexity and nuances of the context. This phase highlights the lack of linearity of the scaling process, as the phases overlap. In socially inclusive scaling, it requires the participation of constituents to address change and any uncertainties.	1) The organisations adapt to address needs in other contexts, such as adapting operating procedures or tailoring projects according to the communities' demands. 2) OPDs accommodate different strategies to achieve their mission.	1) LDPA branches have different programming to the LDPA central office in the Vientiane capital. The AfA model transfer (scaling out) to Pakse has involved adaptations such as the reduction and/or waiving of school fees, and a different organisational operational structure (more flexible, combining roles and responsibilities due to the low number of staff). When QLA replicates in other provinces and districts, it addresses specific concerns and addresses those needs in the projects. 2) Adapting to deliver better results, such as adapting the contents of a training programme to other audiences in the case of LDPA-DRET training.	<i>"We found one case in Kham district. That person, she is around 13 years old and then she would like to go to school very much, but she couldn't have access to school; and then you know many times when we try to help this person and try to get her to the school, it was very difficult because that person she couldn't walk. She was in a wheelchair, so I need to manage this case you know, because I would like to ask QLA to follow like what I am doing to help people like this. And when we discussed first steps that we need to ask, that persons no family, we need to ask that person. We ask what you need and how we can help you, so that she is will like to school, but the problem is that I can't access the school"</i> (Director of QLA, personal communication, March 2018).
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Some practices that were identified might not be overtly innovative. However, OPDs such as the Lao Disabled Women's Development Centre (LDWDC) identified its good practice as innovative because they were first to implement a programme for vocational training for women with disabilities (P4). LDWDC is the only organisation working for women with disabilities since 2001, as recalled by one of their staff members (P4). Moreover, identifying a practice becomes a process of ownership. For example, the LDPA reclaims as theirs the DRET from Power International (a former charity based in the UK); DRET is a programme to raise awareness of the rights of persons with disabilities (P7). Indeed, OPDs recognise their own practices and successes because they are able to judge their benefits; such as the benefit of introducing voice programmes in computers at the National University of Lao to provide accessible information to persons who are blind (P3).

As presented in Table 2, it is evident that scaling has happened or is happening. Some OPDs' practices are currently being scaled, as there are indications that the practices that were piloted are expanding, such as the QLA's Persons with disability Inclusive Committees (PICs). PICs are district committees with representatives from the Ministry of Labour and Social Welfare, which are organised to support persons with disabilities (P8). PICs work to improve efficiency and coordination

amongst district and provincial authorities. The QLA's project began by establishing one PIC and, within a year, PICs were established in five districts. At the same time, AfA has expanded their model in other provinces, without realising that this constitutes scaling (P10). AfA has a centre for children with autism, founded in Vientiane in 2009. In 2017, AfA expanded to Pakse district in Champasak Province. The scaling process is supported by the strong leadership of the AfA director and Board of Directors. The AfA director has supported parents in other provinces to start their centre, following the approach of the centre in Vientiane (P10). Another example of scaling is the work of LBA and VDBA in supporting blind students and negotiating an inclusive model at the National University of Lao, where they have reportedly increased the number of students every year since they started (P1).

OPDs are aware of what is needed for their organisations to scale (OPDs' Workshop, May 24, 2019). Most mentioned technical expertise. While there is a lack of training, new issues emerge that need to be addressed, which require learning and training (P8). OPDs have also taken 'adapting' into consideration, such as LBA's plan to update voice software to use it for different interfaces such as smartphones (P3).

Scaling is a concern for all OPDs. Planning is one of the weakest points addressed by the participants at the workshop, and funding is highlighted as a major problem (OPDs' Workshop, May 24, 2019). Furthermore, as they are occupied in their day-to-day operations, OPDs are struggling with documenting their projects, programmes and policies; they also require guidance on how to do this. It would be useful to document how they have been implementing projects on the ground, to understand their model and to inform their strategic planning (P10).

OPDs use different strategies to increase the impact of their work, which overlap across the planning, implementation and adapting scaling phases (Table 2). One example is inviting the Lao PDR government (Ministry of Education and Sports) to participate in study tours in other countries such as Thailand. As contended by the president of LBA, the government may then be more receptive to experiences in similar contexts and willing to invest in adapting practices. Although OPDs are not formally planning to scale, the study findings indicate that the OPD network is providing a platform to promote OPD activities. The OPD network advocates for disability rights at the national and regional levels in South-East Asian countries (P1).

DISCUSSION

The results show eight emergent themes from the data. OPDs seek government support to implement their activities. Legal registration is important for OPDs, and OPDs who have not obtained registration are trying to do so. OPDs' operational challenges can also influence the scaling process as potential facilitators or barriers. Participants recognised that partnering with other OPDs supports them in advancing their agenda. When policy implementation is lacking, this could be one of their priorities.

Participants indicated that their OPDs were scaling, although they did not appear to plan or document how such scaling happens. To inform their scaling practices, OPDs therefore require a systematic approach that sets out specific steps to scaling. Although OPDs' practices were related to particular scaling phases, participants did not view this as scaling. While OPDs do not appear to have a formal scaling plan, the OPD directors who were interviewed acknowledged what was required in terms of improvement and expansion, as well as their limitations. For example, the director of AFD reported that their plan was to expand to other communities and receive training in Lao sign language, especially in rural areas, by working in schools and with other organisations (AFD director, personal communication, March 2018).

In relation to implementing scaling of OPDs' good practices, participants' accounts were fragmented and undocumented. However, AfA is an example of scaling implementation, whereby the centre in Pakse demonstrates that scaling is being implemented by a group of parents trained by the Vientiane centre. LDPA is another example of scaling implementation by replicating their branches in other provinces; but as they have grown, they have lost proximity with their community members as they are represented through the branch's Boards (LDPA Annual Meeting, December 2018). OPDs that have gone through incipient scaling have adapted their interventions according to the context. As the AfA director relates:

“Every province has their own unique thing and I don't want to sort of copy what we have in Vientiane everywhere” (personal communication, November, 2018).

In the five stages of scaling, the need to include the results of previous interventions in the planning process is emphasised, as an ongoing learning process. However, it is uncertain how OPDs are managing knowledge-transfer, such as AfA's

replication of their centre in other provinces. OPDs have learning tools such as surveys and evaluation questionnaires, but not for the scaling process. External evaluators used some of these tools to evaluate OPDs' performance and report back to the funder. The evaluation tools at the end of a project follow up the initial indicators in the funding proposal, some being rather ambitious such as contributing to the National Social and Economic Development Goals, and others being modestly related to OPDs' initiatives such as improving teacher training at the autism centre (Wardle & Phandanouvong, 2018).

Overall, OPDs' scaling practices are more a spontaneous response to current needs than planned scaling within the five-phases scaling framework. In this context, OPDs' good practices are scaling in the four directions of the framework, but are unrecognised as scaling. Indeed, examples of each of the four directions were found: scaling up – influencing institutional change (e.g., OPDs' network and their influence in the drafting of the disability law); scaling out – replicating and expanding (e.g., replication in the AfA Vientiane centre in Pakse and the QLA-PICs in other districts); scaling in – strengthening OPDs (e.g., IDU becoming IDA, registering as an independent association); and scaling down – allocating resources at the community level (e.g., LDPA allocating resources to self-help groups).

Furthermore, it was found that scaling directions overlap. For example, the expansion of AfA to other provinces (scaling out) led to a governance structure to operate in Pakse and Vientiane (scaling in). The LBA is another example of the overlap of scaling directions, where the organisation is raising awareness with the community to scale up, advocating for adequate services for students who are blind, and scaling out to address other disabilities and departments at the university. However, the organisation understands that in order to scale out, they need better infrastructure and communication within other departments at the university beyond the English department (P1).

OPDs are therefore scaling in different overlapping directions. Importantly, however, further research is needed in relation to OPDs' choice of strategies and the outcomes depending on the scaling direction taken, and considering that one scaling direction may lead to overlapping scaling directions. Despite the scaling examples provided, these OPDs' good practices are unnoticed by other organisations, as OPDs are not documenting the steps taken and improvements made. Participants communicated how their OPD was expanding. For example, the president of LBA explained in relation to their success:

“First thing you have to do is to do a fundraising. First to interest donors and organisations, what we have to do is a lot of advocacy to attract their attention to invest in our programmes especially for the blind to access education and second to teach the blind to know how to use the computers because there are a lot of blind that still can’t use the computers. And after that we can teach them how to access information and after they know how to access information they can go to school or to university” (P3).

Although participants did not recollect a planned scaling process for the OPDs’ good practices, it is clear that OPDs recognised what was needed to scale. When asked how they would scale their sports activities, one of the OPD directors specified:

“By bringing other children from poor regions, mainstreaming disability in the schools, go to the communities”.

This participant then described the steps:

“First, finding the statistics of children and young people with disabilities in the different districts, going to the government district to the welfare office because they have the numbers, then to the school, then organising a campaign that provides information, then organising the activities” (P6).

The findings have shown that OPDs indicate scaling in their practices, but do not use systematic planning processes for scaling. Furthermore, OPDs are inclusive of their members and non-members, including persons with disabilities. However, little evidence was found as to how they do this. The OPD network guarantees the involvement of OPDs and all their members, due to the relatively manageable membership size. However, a predicted growth in the number of OPDs will transform the network space, which should be considered for further studies.

Limitations

The results of this study derive from OPDs in one context. Furthermore, a large representative sample was not used for this study. It is therefore important to caution against generalising findings from this study to other contexts, in light of there being a wide diversity of OPDs, policies, and practices. Nonetheless, little is known about how scaling occurs in practice and the capacity of OPDs to undertake scaling, particularly using qualitative methods. This research has aimed to address this gap in the literature.

Challenges of the study also included the language barrier between the interviewer and the participants. However, attention was given by the researcher to other participant cues and the context in which the interviews were conducted. For example, all of the interviews were conducted in the OPDs' venues, followed by a tour to appreciate their work.

CONCLUSION

A good understanding of how to scale would facilitate OPDs in expanding their projects to other geographical areas and in advocating for the government to adopt projects after international funding ends. This research shows that OPDs are implementing good practices that need to be diffused and scaled purposely and systematically. However, for OPDs, it is a continuous struggle to significantly influence policies and deliver services to more persons with disabilities. Scaling requires the organisation to invest resources that they simply do not have.

Due to the specific context of Lao PDR, OPDs' projects are tied to international donors, their funding is not diversified, although their actions are controlled by the government. Moreover, scaling involves engagement with multiple stakeholders, including other organisations, government, and international non-governmental organisations. Scaling is therefore challenging for OPDs. OPDs may be aware that they are following a path to scale and acknowledge their own good practices, but they have difficulty in systematically planning to scale.

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Appendix A

OPDs in Lao PDR

Name of Organisation	Year Founded and/or Registered	Members/ Beneficiaries	Female Members/ Beneficiaries	Area of Influence	Targeted Disability Population	Areas of Work
Association for Autism (AfA)	2012 (year registered)	88	18	Vientiane and Pakse	Children with autism	Inclusive education
Association for the Deaf (AFD)	2013 (year founded)	2,914	1,160	Vientiane	Persons with hearing impairments	Rights promotion
Lao Disabled People's Association (LDPA)	2011 (year registered)	13,393	9,116	Vientiane and provinces	All disabilities	Rights promotion and income generation
Lao Blind Association (LBA)	2012 (year registered)	75	38	Vientiane	Persons with visual impairments	Inclusive education
Lao Disabled Women's Development Centre (LDWDC)	1990 (year founded)	945	930	Vientiane	Women with disabilities, particularly physical disabilities	Income generation
Quality of Life Association (QLA)	N.D.	N.D.	N.D.	Xiang and Hoang	All disabilities	Income generation, health, rehabilitation, service referrals, and income generation
Saysetha District for Disabled People Association (SDDPA)	2014 (year registered)	687	126	Vientiane	All disabilities	
Intellectual Disability Unit* (IDU)	2008 (year founded)	135	54	Vientiane	Children with intellectual disabilities	Inclusive education
Vocational Development for Blind Association (VDBA)	N.D.	N.D.	N.D.	Vientiane	Persons with visual impairments	Inclusive education

*In 2019, the OPD became the Intellectual Disability Association, receiving its own registration.

Source: Presentation at the Third Disability Forum, March 2018, and personal communication with OPDs' directors (2018-2019).

Appendix B

Interview Schedule for OPDs

Areas to cover:

- General information about the interviewee (years working in the organisation and role)
- General information about the organisation (year founded, mission, and vision)
- Organisation's relationships and networking (relationship with other organisations, communities, government, funders, and others)
- Areas of expertise (main projects, and those related to women and girls with disabilities, geographical areas covered)
- Practice presented and selected by HI-Making it Work (description and success)
- Identifying good practices that are particularly related to working with women and girls with disabilities (criteria to select good practices)
- Follow-up questions on scaling up (using data from the first round of interviews, ask follow-up questions about challenges and useful resources for scaling up practices)

Interview guide:

1. Demographics:
 - How long have you been working in the organisation?
 - What are your main responsibilities?
2. Background of organisation:
 - When and why was the organisation founded?
 - What is the mission of the organisation?
 - What are their main projects?
 - How is the organisation's engagement in policy-making processes? What are the contacts with policy-making processes? How do you contribute?

- What is the relationship with other stakeholders? Other organisations?
- What is the relationship with the government?

3. Good practice:

- How do you describe the organisation's good practice?
- What makes your practice a good one?

4. Scaling up:

- How are you planning to scale up your practice? Or what are the steps that you have followed to scale up your practice?
- What do you think will need to happen for the scale up to be successful?
- What would you see yourself using to scale up from what you learnt in this workshop?

Appendix C

Workshop Plan

Objectives for the OPDs

OPDs' good practices:

1. OPDs recall their good practices and recognise what made them successful
2. Identify strategies employed that were useful to the success of the practice
3. Identify the changes produced – anecdotally or through story-telling

OPDs scaling their good practice:

1. Understanding what scaling is and how it is conceptualised in their context
2. Identify the scaling dimensions and how these occur in their organisation
3. Identify actions that have unintentionally led to scaling their good practice

Agenda:

Activity	Purpose and Description
Introductions – explaining the purpose of the workshop, and providing a quick summary of the status of the research project.	Ensuring that everyone knows who is in the room and what we learnt from everyone's expectations.
Part 1. Revisiting the good practice – work in teams and choose one to present (2 to 3 groups).	<p>Recalling good practice. Each organisation will describe their practice to the other team members:</p> <ol style="list-style-type: none"> 1. Briefly describe your practice and recall the objective. 2. In what terms was your practice targeting persons with disabilities to strengthen their inclusion? 3. What makes your practice a good one? 4. Have you developed or improved your practice? How? 5. Tell a story of your practice success.
BREAK	
Part 2. Understanding scaling and the scaling process.	<p>Discussing the scaling dimensions, and recognising the types of scaling that my organisation is implementing.</p> <p>In what ways is my organisation scaling and, if not, my practice?</p>

Part 3. Briefly explaining components of a scaling plan.	How are you planning to scale up your practice? Or what are the steps that you have followed to scale up your practice? What do you think is needed for the scale up to be successful?
Conclusions.	<p>Workshop evaluation:</p> <ol style="list-style-type: none"> 1. Did you find the workshop useful for your organisation's work? 2. What could be improved? 3. Are you interested in a second workshop to follow up the work that we did here? 4. What would be important for you to learn specifically on scaling?
END OF WORKSHOP	

Inclusive Education and Disabilities: Narratives from Ghana

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ABSTRACT

Purpose: *Inclusive Education (IE) has been recognised internationally as the ideal model of educational access to all. Despite this, it faces many challenges. The present study explored the narratives of 10 participants with diverse disabilities in Accra, Ghana, keeping the focus on (a) how children with disabilities in an Inclusive Educational facility understand their educational experiences, (b) how they perceive their relationship with peers and teachers in school, and (c) how accessible they find existing school infrastructures.*

Method: *Using a phenomenological approach, data was generated through in-depth interviews with 10 participants from two selected schools.*

Results: *The experiences of participants, in some instances, were found to be two-sided. While participants felt accepted by some of their peers, they also experienced bullying by others. While some of the teachers were supportive, others were not. All the participants agreed that the physical school environment was disability-unfriendly.*

Conclusion: *Despite limited participation of children with special needs, greater stakeholder commitment was observed. This is promising for the future success of Inclusive Education in Ghana.*

Key words: *perception, peer acceptance, stigmatisation, mainstream school, phenomenology*

INTRODUCTION

Inclusive Education, which is every child being part of mainstream classrooms and receiving quality learning with adequate help, is internationally understood as a basic human right. 'Inclusive education thus entails that learners with diverse

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barriers to learning be included and receive appropriate instruction in general education classrooms' (Nkoma & Hay, 2018).

Access to education is conceptualised as a fundamental human right of persons, irrespective of background or socioeconomic status (Pather, 2019), thereby calling for education to be made available to all (Imaniah & Fitria, 2018). Considering the difficulties faced by children living with a disability, the concept of Inclusive Education (IE) was introduced. Prior to this, children with a disability were educated by economically capable parents in segregated institutions, which on an average, are very expensive (An, Hu & Horn, 2018). Not with standing the cost, Aron and Loprest (2012) believe education plays an important role in enhancing the social and economic prospects of persons living with a disability, making the idea of IE important (Imaniah & Fitria, 2018).

The concept is introduced by Imaniah and Fitria (2018) as a guide to all educational policies and practices towards reformation or structuring to increase educational access. Similarly, Pather (2019) perceives IE as a social and political undertaking that calls for a drastic restructuring to guarantee excellent education for all. In light of these arguments, IE is not a mere placement of children with disabilities in regular schools, but also paying the necessary attention to the conditions under which all children are educated. Inclusive Education should therefore be 'the practice that provides school experiences to children with special needs, in the same school and classrooms they would have attended anyway had they not had special needs' (Pramanik & Bag, 2013).

Inclusive Education is faced with many challenges. Pather (2019) argues that understanding what IE means and stands for is significantly surrounded with tensions. According to Pather (2019), IE as introduced at the Salamanca Conference decades ago, targets meeting the needs of not only children living with disabilities but also all persons with special needs. Pather (2019) believes this is not well understood and appreciated by some nations, especially those in Africa and Asia. In some nations the absence of legal instruments demanding that public schools enroll children living with a disability hinders the educational access of children with disabilities. This struggle ultimately leads to the establishment of more segregated specialised schools in some countries like China (An et al, 2018).

An et al (2018) further noted that inflexible class structure, large class size, and teachers' lack of experience and preparation to support students with learning challenges, were a hindrance to the success of IE. While teachers are well-trained in specialised subjects, they have little to no knowledge on how to handle children

living with disabilities. The large class size also limits the teachers' interaction with each child. Negative teacher attitudes and limited resources could lead to inadequate support from teachers to the students who need help (Nkoma & Hay, 2018).

In Africa, in addition to poverty, Pather (2019) cited limited or lack of human and material resources, lack of qualified teachers, rigid curricula, poor conceptualisation of inclusion, and lack of parental participation, among others, as particular barriers to IE. In their study in Zimbabwe, Nkoma and Hay (2018) found that there is much pressure on mainstream schools to raise the academic standard as measured by the average performance of students. This prevents school heads from admitting students living with learning disabilities.

Tracing the history of children living with disabilities in Ghana, Nketia (2019) revealed they 'are often locked up, hidden, abused, killed or excluded from mainstream society and education'. Children were treated in such a manner based on the belief that disability is a manifestation of the workings of evil powers, curses from idols due to the wrongdoing of a family member, etc. This practice is outmoded in most urban areas of Africa, and in particular Ghana, given legislations safeguarding the rights of persons living with disabilities.

However, the notion of Pather (2019), regarding Inclusive Education in Africa, prevails in Ghana. According to Okyere, Aldersey and Lysaght (2019), Ghanaian policies are yet to pay the needed attention to teaching approaches and structural transformations to make IE a success. Earlier studies, such as the one by Boots and Owusu (2013) that focused on intellectual disability (IDD), found that only a few children access government-supported education. Nketsia, Saloviita and Gyimah (2016) revealed that though the idea of IE is laudable, Ghana is not prepared for its practice. In support of their argument, Nketsia et al (2016) found inadequate teacher preparation, unpreparedness of teacher educators, inadequate inclusive instructional strategies, and lack of teaching and learning materials. Furthermore, Deku and Vanderpuye (2017), focusing on the perspectives of teaching in IE facilities, concluded that the curriculum of the Ghana Education Service (GES) is inappropriate for IE. Similar findings were observed by Agbenyega (2007) and Opoku, Mprah, Agbenyega, Badu and Mckenzie (2017).

The above findings indicate that there has been a great deal of study on IE in Ghana but, as Okyere et al (2019) called for, there is the need to access the narratives of children living with disabilities in IE institutions within the country.

Objective

The current study explored the experiences of children living with disabilities in IE institutions in Ghana, in order to understand:

- (a) How children with disabilities in an Inclusive Educational facility understand their educational experiences;
- (b) How children with disabilities perceive their relationship with peers and teachers in school; and
- (c) How accessible children with disabilities find existing school infrastructures.

METHOD

Study Design

A phenomenological perspective was adopted where participants gave their subjective experiences of being in a mainstream IE facility. Narratives were generated through in-depth interviews (Qutoshi, 2018). In looking for the meanings people give their daily experiences, Creswell (2007) recommends a qualitative approach as the most suitable. As noted by Denzin and Lincoln (2018), the design enables researchers to obtain in-depth data about the issue under study.

Study Site

The study was conducted in two selected schools at the Ashiedu Keteke Sub Metropolitan District Assembly of the Greater Accra Region of Ghana. The district is one of the 10 Sub Metropolitan District Councils of the Accra Metropolitan Assembly (AMA), with a population of 119,478 representing 6% of the population of Accra, the capital of Ghana (Ashiedu Keteke District Environmental Sanitation Strategy Action, 2013).

These schools were selected because of their designation by the Ghana Education Service (GES) as IE facilities and because they have students with diverse disabilities.

The first selected school, established in 1959, had 346 pupils with 12 classroom teachers and a Special Education teacher. The second, established in 1930, had 850 pupils with 14 classroom teachers and a Special Education Teacher . Each school was headed by a teacher and had a shift system where some children come to school from 8am to 12noon while others begin at 12 noon and close at 4pm.

Study Population

Ten children, between 8 and 18 years of age, participated in the study. Five of them were girls and the other five were boys. Although there were 158 pupils with disabilities in both schools as per the records of the two Special Education Teachers, the difficulty in obtaining parental consent and participant assent (Convention on the Rights of the Child - CRC, 1989) as well as the selection criteria itself reduced the number of participants.

Inclusion criteria required the child to be:

- Living with disabilities,
- Able to communicate verbally without assistance, and
- Enrolled in the selected schools based on IE.

The Special Education teachers, who had been working with each of the children for at least a year, were consulted to ascertain the children's ability to participate in the study. This helped in developing the selection criteria for participants.

Data Collection and Analysis

Research studies focused on children living with a disability call for attention to data generation. In view of this, the study constructed data with children who could communicate effectively without assistance.

Data was generated through in-depth interviews. The approach gave each participant the required time to make meaning of their experiences. It aided seeking further clarification when narratives were not self-explanatory (Boyce & Neale, 2006). The researchers gathered data with most of the participants in their local languages (Ewe, Twi and Ga). All interviews were conducted in participants' homes so that the participants were in a familiar environment and were consequently less stressed.

Each interview lasted from 50 minutes to an hour and 15 minutes. All interviews were audio- recorded and later translated and transcribed into English by the researchers. These measures are encouraged by Wyman et al (2019) when interviewing children with intellectual disabilities, as those with mild to moderate intellectual disability are capable of recollecting experiences in a coherent manner, given some cautions such as those taken by this study.

Analysis was done using a framework analytical tool. This approach provided the opportunity to move back and forth in constructing themes, without losing the core expressions within the participant narratives. The raw data moved back and forth through several stages. The first stage was identification of concepts, which involved reading through a portion of the transcribed data for similar ideas. This was followed by index construction and application, which involved the search for similar identified ideas in the rest of the raw data. Data sorting, which was the next stage, ensured the categorisation of the narratives according to the identified ideas. The ideas were then built into thematic themes at the following stage. These themes were then presented with their associated narratives for the development of broader themes. The broader themes constituted the major study findings (Ritchie, Spencer & O'Connor, 2003).

Ethical Consideration

Ethical approval was obtained from the Ghana Education Service office of the Accra Metropolitan Assembly. Approval was also obtained from the leadership of the schools. Written parental consent and, later, verbal consent from the parents who signed their consent forms was established. Assent was also obtained from the participants. All these approvals were received after the purpose of the study was explained to each category of people. At the beginning of the interview, every child was informed and encouraged to voluntarily participate or withdraw if so desired. Furthermore, each interview subject was given a pseudonym to conceal participant identity. The audio-recording of the interviews was deleted after the analysis of the data. The transcripts will also be deleted after dissemination of the findings.

RESULTS

The study explored the experiences of children with disabilities in a mainstream school. Four themes emerged: participants' perception of inclusive education, peer acceptance, teachers' attitude, and school infrastructure and other educational facilities.

Primary education in Ghana begins at 6 years of age. For the study, 10 participants (between 8 and 18 years of age) were interviewed. While 5 were in primary one, 2 were in Junior High School (JHS), another 2 in primary class six and 1 in primary class five, as indicated in Table 1 below.

Table 1: Demographic Characteristics of Child Participants

Pseudonyms	Age (Years)	Education	Disabilities
Vincent	17	JHS 1	Intellectual and learning disability and dysgraphia
Bismarck	18	JHS 1	Speech impairment, hard of hearing and learning disability
Tracy	17	Primary 6	Epilepsy and intellectual disability
Helen	18	Primary 6	Low vision, hearing and speech impairment
Ofei	15	Primary 5	Mobility challenged, intellectual disability and dysgraphia
Rosemary	10	Primary 1	Intellectual/speech impairment, dysgraphia Attention Deficit Hyperactivity Disorder (ADHD)
Adwoa	13	Primary 1	Mobility challenged, low vision and speech impairment and dysgraphia
Linda	8	Primary 1	Intellectual disability, epilepsy and speech impairment and dysgraphia
Joseph	10	Primary 1	Mobility challenged and speech impairment
NiiAryee	17	Primary1	Mobility challenged, intellectual and speech impairment and dysgraphia

Source: field data

Participants' Perception of Inclusive Education

Several studies have been done on how inclusive the practice of Inclusive Education really is and what the ideal situation should be. In the current study, participant narratives portray some positive and negative sides of the practice as it pertains to Ghana.

A 17-year-old boy reflected,

“This school is not helpful to me to learn. When I write, the other children laugh at me that I don’t know how to write so I should leave the school. It is bad to be in the same class with the other children who always laugh at me” (Vincent, JHS 1).

Mockery was a major concern for seven of the participants who were all teenagers. To be mocked by colleagues in JHS 1 could be damaging for any teenager. Considering his age, Vincent could have been in his first year at university.

A 17-year-old girl and a 15-year-old boy added,

“When teachers teach, and I don’t understand, and I ask some of my mates they ignore me.... Even today, we had dictation; I didn’t know what to write when I asked the one sitting by me, he ignored me” (Tracy, P6).

“Others ignore me when I ask them for help when exercises are given. I feel shy when they ignore me” (Ofei, P5).

These narratives indicate the children’s frustration and inability to follow lessons like their peers do. The usefulness of the school then is reduced to the child’s ability to progress academically.

Peer Acceptance

The study noted that participants suffer humiliation based on their disability status. This could be likened to bullying. All the participants, except one, mentioned this aspect during their interviews. For instance, Tracy (17 years old), Linda (8 years old), and Adwoa (13 years old) mentioned:

“The other children laugh at me because my legs twist and look crooked when I run” (Tracy, P6).

“One of the boys is always teasing me that when I am hungry then I intentionally fall for them to give me milk. I know that I am not well and not that I intentionally collapse” (Linda, P1).

“There is a girl here, she has been beating me. Others have also been pushing me down” (Adwoa, P1).

Bullying may occur in most schools. However, when bullied, children would expect to find their teachers helpful. This study found otherwise, based on the narratives of 6 participants.

“I’ll be there, and the other children will be shaking me saying ‘Mommayenteten’ataade’ (let’s tear his uniform). They do that and my uniform gets torn or the buttons get loose and I must fix it” (Vincent, JHS 1).

“The other children throw stones at me. If I report, the teachers say ‘Ee, you, you like complaining’ and this makes me sad” (Rosemary, P1).

“... a boy killed a housefly and put it in my food. I threw the food away and bought another. ...Madam only told me not to mind him” (NiiAryee, P1).

However, two of the participants were also encouraged to be part of the school.

“I am happy to be in school. In school when I ask my friends for something, they give me. We eat each other’s food” (Tracy, P6).

“They encourage me not to worry but study hard. I should learn little by little and

I'll understand. They also encourage me to pray to God to heal me" (Tracy, P6).

"I am happy in school. I play football and dance with my classmates. I get off my wheelchair and join them dancing" (Joseph, P1).

Infrastructure

The study found that all the participants were unhappy with their school environment.

"The environment is not disability friendly. I don't know when my sickness will attack me. I can fall at any time anywhere and hit my head with the stones everywhere on the compound. I usually stay in the classroom" (Linda, P1).

"I find it difficult to move on the verandah and to use the stair.... some of us fall and hurt ourselves" (Helen, P6).

"The compound is full of big stones, un-levelled, and we often get hurt. We sometimes remove our shirts while in class because there are no windows, so the room is dark and hot" (Bismarck, JHS1).

"The inaccessible nature of the school is affecting those of us who are sick. For me, my sister attends the same school. She brings me to school, helps me get to my class and during break periods, she also helps me to urinate. She carries me with the help of her friend" (Adwoa, P1).

Teachers' Attitude

Narratives of two participants indicated that due to difficulty in following lessons, teachers engaged some of them in menial jobs while they were teaching the other pupils.

"... if the trash bin is full, teacher always tells me to empty it while my mates are learning, because they say I don't know how to write" (Vincent, JHS1).

"When the teacher teaches and we don't understand, then he will say 'Are you stupid?'" (Bismarck, JHS1).

Meanwhile, four participants also recounted positive moments with their teachers, despite other difficult times.

"When I get the epileptic attack in school, they call my parents to come for me"(Linda, P1).

"The class teacher pays my exams fees. Sometimes she teaches me during break" (Tracy, P6).

"... my teacher gives me money, watermelon, and when she teaches and I don't understand she does not insult or cane me" (Nii Aryee, P1).

"My teacher gives me exercise book, pencil, crayon, eraser and ruler to write" (Joseph P1).

The narratives above show that participant appreciation is linked to the extra help received from teachers. This help is extra because it is not built into the general school system.

Repetition and Withdrawal

Moreover, the study found that all participants were in lower classes than they ought to have been according to their biological age. As previously stated, primary education in Ghana begins at 6 years of age. Linda, 8 years old, was the youngest and in primary1, instead of primary 3, or at least 2. Participant narratives indicated that some of them have repeated several classes.

"... Because of my condition if they repeat me again, the children will laugh at me. I want to go to the school that they will help me" (Vincent, JHS1).

"I don't want to be repeated again. If they do, I will not be happy. I have been repeated four times - twice in class 2 and twice in class 3. I also don't want the head to ask me to withdraw. I love school" (Tracy, P6).

Tracy's narrative suggests that pupils could be asked to quit school because of poor performance. Repetition and being asked to withdraw were a major concern for all participants.

DISCUSSION

The essence of carrying out a project is meaningless if the dictates of the project are not well understood. In Ghana, since the Salamanca Declaration over two decades ago, only a few schools are designated Inclusive Education facilities. The study found that while some participants felt accepted by their peers, others experienced bullying. It was also noted that the attitude of the teachers, as narrated by some participants, could serve as a deterrent in experiencing satisfaction with Inclusive Education. The study also found that the school environment was a hindrance to fostering IE.

Peer acceptance was vital to almost all participants. The narratives clearly show that the children do not have the needed help with extra learning. In the absence of this, participants endure mockery from their peers for poor performance. This disputes the findings of Nkoma and Hay (2018) which suggest that the presence of children with disabilities in mainstream classrooms is beneficial to those without a disability. In this study, to be different is rather to be a target of mockery. Agbenyega and Deku (2011) did not mince words in their findings, which pointed to the fact that Ghanaian schools are not prepared to embrace diversity.

The study found that some participants had to endure bullying by their peers. This gives credence to the study of Asamoah, Ofori-Dua, Cudjoe, Abdullah and Nyarko (2018). Focusing on visual impairment, they found that students without disability are not in favour of IE. It may be argued that bullying occurs in every school, irrespective of whether or not it is an inclusive facility. It is possible that children without disabilities also experience bullying. This, however, does not make it right, given the psychological trauma that bullying can result in, as noted by Peters, Riksen-Walraven, Cillessen and De Weerth (2011) who mentioned that it could lead to high levels of stress and other complications.

Participants' narratives also relate to inappropriate school infrastructure which limits access independently. In an atmosphere of bullying and mockery, inappropriate infrastructure puts fear in children about their safety in school. In confirmation with Agbenyega (2007) and Deku and Vanderpuye (20017), inaccessible classrooms and unsatisfactory physical environments are impediments to successful Inclusive Education in Ghana. This disagrees with the view of Aron and Loprest (2012) and Habibi (2017) that IE affords children with disabilities greater access to public education alongside children without disability. There is agreement with Gadour (2019) that without structural modification, placing children with disabilities in mainstream schools amounts to 'dumping' them.

The study further notes the inability of teachers to protect participants from bullying, and the occasional tendency to subject them to menial tasks. Narratives recounted the performance of menial jobs during class hours, and of being subjected to verbal abuse and different treatment by some teachers. According to Nkoma and Hay (2018), though teachers support the philosophy of IE, only a few are willing to be involved. The implementation of Inclusive Education in Africa, as Pather (2019) noted, is challenged by systemic and attitudinal difficulties.

Meanwhile, the narratives also reveal that not all teachers lack friendly attitudes towards pupils with disabilities. Some teachers teach participants after school, pay their examination fees, and provide writing materials and food. Most of these duties should have been performed by parents and the government. Ghana boasts of free compulsory basic education but, due to lack of resources, public schools still levy pupils to print examination questions. Teachers feeding pupils also suggests a lack of parental involvement. Amponteng, Opoku, Agyei-Okyere, Afriyie and Tawiah (2019) stressed the need for parents to fulfil their obligations in aid of successful IE.

Finally, participants feared being forced to repeat class continuously or being asked to withdraw from the school due to poor academic performance. Aron and Loprest (2012) noted that children with disabilities sometimes lag behind their peers in education due to low expectations and the probability of not taking the full academic curriculum. Meanwhile, Pather (2019) also mentioned inflexible curriculum and pedagogy as some of the challenges facing IE in Africa. The two aforementioned studies are vital in understanding the plight of the participants. In their study in Zimbabwe, Nkoma and Hay (2018) identified that some schools will not admit children with certain types of disabilities for fear of lowering the academic performance of their institutions. If IE is well understood in Ghana, pupils with disabilities should have their own individual mode of assessment and not be subjected to the rigid mode that is currently practised, where all pupils take the same examination.

The findings of the current study support previous studies while uniquely highlighting how some experiences could be both positive and negative in the same institution. From the standpoint of research, a larger study is needed to explore the experiences of children with disabilities in schools.

CONCLUSION

The study explored the narratives of 10 participants with diverse disabilities, based on:

(a) How children with disabilities in an Inclusive Educational facility understand their educational experiences, (b) How children with disabilities perceive their relationship with peers and teachers in school, and (c) How accessible children with disabilities find existing school infrastructures.

The study found the experiences of the participants to be double-edged in some instances. For example, while participants felt accepted by some peers, they also experienced bullying by others. This also applied to teachers' attitudes. While some of the teachers were supportive, others were not. There was agreement among all participants that the physical school environment was not disability friendly.

In general, the Ghana Education Service needs to ensure that all schools adhere to its anti-bullying policies, by educating both pupils and teachers. There is also the need to train all teachers in working with children with disabilities. Structurally, schools should be made accessible to all students.

It is suggested that the Government of Ghana take a leading role in policy formulation and financing the implementation of such policies. Parents of children with disabilities also need to be encouraged and educated regarding the unique needs of their children. Those parents who are unable to meet their children's needs could be empowered to fulfil their duties.

It is believed that Ghana could achieve success in Inclusive Education with the implementation of these suggestions.

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“I Need to Love and to Be Loved”: Perspective of Young Adults with Hearing Loss in Kabul-Afghanistan

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ABSTRACT

Purpose: *This research aimed to explore love and belonging or social needs, of young adults with hearing loss in Kabul, Afghanistan.*

Method: *A qualitative research method specifically, the phenomenological approach, was adopted to conduct this research. An in-depth semi-structured interview was used to interview ten participants.*

Conclusion: *Overall, two themes and four sub-themes were derived from thematic analysis. The finding indicates that social support from family members and people in the surrounding, and a sense of belonging are fundamental social needs of people with hearing loss. Further research is needed to investigate the reasons behind the unmet social needs of people with hearing loss.*

Limitation: *The major limitations of the study were - lack of official data regarding people with hearing disability in Afghanistan, non-availability of sign language interpreters, and cultural constraints faced by female study participants.*

Key words: *Love and belonging needs; social needs; young adults; hearing loss; Kabul*

INTRODUCTION

Love and belonging is the central level of the human motivations theory which is called social need as well (Maslow's hierarchy of needs). Fulfilment of this need requires the ability to consistently receive love from others, give love to others, and being accepted by members of a group like family, friends, colleagues, religious communities, and so on (Cleary, 1996). Hammell (2014) also mentioned

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that love and belonging needs could be fulfilled in different environments like in the vocational environment, in religious communities, within the family, and in other groups as well. In the author's view, love and belonging is a meaningful accomplishment, and a motivation factor in achieving additional needs.

Most studies have shown that the need to be a part of a group such as family, a group of colleagues in a workplace, a group of friends, or other social groups relates to love and belonging (Aruma & Hanachor, 2017). The most vital point to be made here is the importance of family and friends in fulfilling the love and belonging needs. The family plays an important role in lives of people, which is clearly visible in most circumstances of people's lives, for example during the time of birth, adoption, marriage or death. Having good friends and family is a big support in the fulfilment of love and belonging needs (McAbee, Dragow, & Lowrey, 2017). People with hearing disabilities have a desire to be a part of group of people with hearing disabilities and receive support from friends with hearing disabilities. The reasons behind this are a deeper level of mutual trust and understanding, sharing a similar culture, having the same language and communication, learning from and with each other, and making them feel that they are not alone (Nikolarazi & Hadjidakou, 2006).

Another part of the love and belonging needs is marriage. Individuals with hearing loss not just regularly choose their friends from people who have a hearing disability too; they also usually marry in the same community (De Veirman, Haage, & Vikström, 2016). Married people may establish a great relationship and they believe that they will gain more independence and freedom, happiness, and peace of mind with each other (De Veirman, Haage, & Vikström, 2016). However, a hearing loss could have a huge impact on a person's marriage opportunities for different reasons. People with hearing loss may face obstacles in communication with the majority of hearing people that they encounter, and they may face difficulties in establishing personal relationships with future spouses

However, the importance of love and belonging and paying attention to the love and belonging needs of people with hearing disability are largely being ignored in Afghanistan. For example, there is evidence about people with hearing disability who have been humiliated and beaten up by the local people. People with hearing disability are at times prevented from going to relatives' houses and denied from attending public events. Disabilities, in general, are considered a shame to the family, and such families may face a lack of access to public buildings, and

the participation of people with hearing disabilities in Afghanistan is the same (Afghanistan Independent Human Rights Commission, 2014).

METHOD

Research Design

This study used a qualitative research approach specifically, the phenomenological method. Given that the study focused on love and belonging needs of young adults with hearing loss it was apparent that the phenomenological research method had to be used.

Participants

Overall, 10 participants - 5 young adult males and 5 young adult females with hearing loss - were involved in present study. Participants were selected based on inclusion and exclusion criteria. Inclusion criteria of the participants were: being amale or female with hearing loss, age between 20 to 40 years old. Participants that were excluded are those who are having some degree of hearing through hearing aids, and those who acquired hearing loss later in their life. The number of participants depended on data saturation which was reached with 10 participants. Data saturation refers to the quality and quantity of information. Data saturation is usually defined at the point when no new information or themes emerge from the collected data (Guest, Bunce, & Johnson, 2006).

Data Collection Procedures

This study has been conducted through in-depth semi-structured interviews with the participants. The in-depth semi-structured interview is one of the most appropriate ways for data collection in qualitative research to find out answers to the research questions from the participants. An interview guide with two parts was used. Part one consisted of demographic information of the participants which include age, gender, educational background, occupation and marital status. Part two of the interview was divided into three questions, and the aim of this part was to explore love and belonging needs of young adults with a hearing loss.

Interviews were conducted in two phases. First, a pilot interview was conducted. The pilot interview was conducted “to allow researchers to practice and to

assess the effectiveness of their planned data collection and analysis techniques” (Engström, Leksell, Johansson & Gudbjörnsdottir, 2016, p. 1074). In this study, the pilot helped to find out the exact length of the interview time, as well as making a decision about final questions for the interview and to understand easiness and difficulty level of the interview questions. Participants were interviewed using sign language and the interview session was video recorded after consent was obtained from the participants. In addition, each interview took a minimum of 25 minutes and a maximum of 45 minutes. For the present study, ethical issues were taken into consideration, because ethical principles can be utilized to direct the research intending to the important and ongoing issues emerging from qualitative research to keep up the rights of the respondent (Orb, Eisenhauer, & Wynaden, 2001).

Regarding the ethical procedures informed consent was asked from the participants after they were debriefed about the purpose of the study. The participants were assured about anonymity as well as confidentiality. They could withdraw from the current research at any moment without giving reasons. In addition, the interviews were video recorded after written consent was obtained from the participants .

Data Analysis

Data was analyzed using thematic analysis, following the six steps suggested by Braun and Clarke (2006). These six steps are: familiarization with data, generation of the initial code, searching for themes, reviewing the themes, defining and naming the themes, and production of the report.

FINDINGS

The aim of this part is to report the findings of love and belonging needs of young adults with hearing loss in Kabul-Afghanistan.

Social Support from Family Members and People in The Surroundings

Social support from family members and people in the surroundings was identified as the first theme for love and belonging or social needs. Based on the information given by participants, there are two sub-themes i.e. ‘positive society attitude’ and ‘social support’.

- ***Positive society attitude***

The majority of the participants emphasized that the positive attitude of society generally appears in the form of respect, encouragement, support, and a sense of security, which plays an important role in the social life of people with hearing disabilities. The majority of participants reported that society's attitude towards them is different. Family members, friends, classmates, and their colleagues (who have a hearing disability) are respecting them, supporting them, encouraging them, and accepting them as they are. Some of the participants shared their experiences as bellow:

"It is clear that my parents and family members have a good behaviour toward me. They love me, respect me, and always support me. Actually, my hearing loss has never been a problem for them, I always feel they treat me the same as my other siblings, I have been given the right of education, and the right to get married by my choice". [Key respondent]

Another participant who was satisfied with his life due to having the greatest friends who has hearing loss stated:

"All of my friends are hearing disabled, and I feel proud and happy whenever they are with me. Besides that, their feelings are the same toward me because we can understand each other easily. To be honest, I have some hearing friends. We also meet each other but we cannot communicate properly, therefore, sometimes they feel bored with me, because they do not want to explain everything they discuss. I also do not feel comfortable with them". [Key respondent]

Some other participants stated that friends, classmates, and their colleagues - people with hearing disability and without - both have a positive attitude toward them. For example, one participant stated:

"I am a social person and I try to make a lot of friends. It never mattered to me that my friends must be hearing or hearing disabled people. I have studied in the same classroom with hearing classmates, and I have found them very good and helpful because their behavior and attitude was positive and friendly. In fact, most of my friends and colleagues are also hearing people and I have very good relationships with them. Previously, because they were less familiar with people with hearing disability, their attitudes were not so positive, but after they met me, their attitudes changed completely. Now, they have a very positive attitude towards me and everyone with a hearing disability" [Key respondent].

Conversely there are some other participants who blamed society for not accepting them as 'normal' or equal members of society, not believing in their abilities and their sympathetic and inappropriate behavior toward them. One female participant described her experiences:

"People in society have a negative attitude toward people with hearing loss. As a hearing, disabled lady, I do not dare to talk to my friends when I am on the way to school. Because we use sign language for our communications, and everyone who sees us will definitely either laugh or ask, why are you moving your hands? Are you crazy? I really feel embarrassed even sometimes, they make me scared".
[Key respondent]

Another participant revealed:

"As far as I have experienced, the attitudes and behaviors of people in society towards people with hearing loss are negative. They are not aware of our needs, our abilities and talents, even they do not know how to deal with a person with a hearing loss. Once I went to a wedding party with my mother, where everybody who met me, they asked my mother about me when my mother explained, and they got to know that I am a hearing disabled lady. Their facial expressions were totally changed, seemingly they were so sad like they had heard the news of someone very dear death. They said to my mom "Ohhh poor she is deaf". It was my first and last time to join a party". [Key respondent]

- ***Social support***

"Social support is defined as the perception or experience that one is loved and cared by others, esteemed and valued, and part of a social network of mutual assistance and obligations" (Wills, 1991, P. 267). In this study, social support is about receiving love, feeling valued, sense of security, respected and accepted by others, feeling encouraged, and feeling of mutual trust, which could be received from family members, teachers, friends, team members, colleagues, and society. The majority of participants were dissatisfied with the level of social support received from society. According to them, social support is one of the most important love and belonging needs of people with hearing loss, but unfortunately, society is not aware of this need. One participant stated:

"I am not satisfied with the behavior of society at all. Because they do not respect me, and they have never supported me. In addition, they have been laughing at me, making fun of me, calling me crazy, and even avoiding collaborating with me". [Key respondent]

Another female participant mentioned that:

“In our society, people with hearing loss are not supported. I am not happy with the behavior of people in society, towards us, especially their behavior with women. Women are very sensitive, and they need to be respected, safe, and valued. For being engaged in social activities I am expecting to be supported. but society is not aware of these all”. [Key respondent]

Another female participant said:

“You will not believe it, from childhood until now, I have no friends. from my classmates, in my relatives, and in our neighbours, I did not make any kind of friendship. Because I was a deaf girl and whenever I was playing with children, for not hearing their voices, they made fun of me. Since then, I have no confidence to make friends. I always try to stay away from everyone in my surroundings”. [Key respondent]

In brief, the first extracted theme about love and belonging needs was social support from family members and people in the surroundings. Receiving support was reported as one of the basic love and belonging needs of people with hearing loss, which appears in the form of a positive attitude, respect, encouragement, support, giving love, value, and a sense of security. Fulfilment of these needs gives them the feeling of self-respect, self-esteem, completeness, and giving them energy in achieving their goals.

Sense of Belonging

The second theme revealed for love and belonging needs is a sense of belonging. According to the findings, a sense of belonging indicates the need for human beings to be a part of a group such as the family, group of friends, and classmates, a group of colleagues in a workplace, social groups. There are two sub-themes that include to love and to be loved on one hand, and building a healthy relationship on the other hand.

- ***To love and to be loved***

According to the participants, to love and to be loved is the basic love and belonging need of all human beings. All human beings may love others and may have the desire to be loved by others. The majority of the participants revealed that people with hearing loss are generally less confident, and therefore they may

need more love and need to receiving more love from family members especially from spouses, colleagues, peers, and friends. This is because receiving love may have a huge impact on their personality, and satisfaction with life, and it gives them a sense of closeness, peace of mind, security, importance, and respect. Besides, it helps to reduce possible fear of failure and motivates people to work hard and achieve their life goals. As one of the male participants said:

“All my family members really love me, respect me and trust me which are valuable for me and my future. When I was a kid, my father died, but my brothers and my mother have always kept loving me since childhood. If I had problems in my studies, if I needed financial support, if I had problems with someone in the community, my family would solve it. All my achievements are just because of my family and their love”. [Key respondent]

Another male participant expressed:

“I am blessed that I have the greatest family, beloved friends, and respectful colleagues. My family loves me, I feel secure and strong, my friends love me, it gives me the feeling of importance and peace of mind, my colleagues love me, and I feel respectful”. [Key respondent]

- ***Building a healthy relationship***

According to the findings, all human beings need to have healthy relationships with family, friends, colleagues, and society because this is an innate need that must be met. People with a hearing loss face many difficulties in building healthy relationships, due to their limited communication. But they need to be part of social groups and to fully participate in social activities. Besides, they may need or want to be member of some organizations such as clubs, religious groups or sports teams.

Some participants provided information regarding their experiences in building healthy relationships. People with hearing disabilities are keen to have a wide range of connections. They do not face major obstacles in building relationships with their family because of their disability (De Veirman, Haage, & Vikström, 2016). However, our findings have shown that some of them especially females face a variety of difficulties in building healthy relationships with friends, colleagues, and society, especially with the hearing population.

Despite this fact, people with hearing disabilities are trying to reduce these problems, making more friends from hearing people, and be involved in social

activities. It is reported by some participants that building a healthy relationship is one of the love and belonging needs. As one of them stated:

“Having good relationship with family, friends, and community is a social need. In my opinion, patience is needed to meet this need. I have been frustrated many times by friends, colleagues, and people in the community, but since I need to have a relationship with them, I go back and talk to them more lovingly, trying different ways to talk to them and to build a strong relationship”. [Key respondent]

Based on some other participant’s responses, building healthy relationships between hearing and people with hearing disabilities is not like relationships among those who don’t have hearing disabilities because their language, their communication and understanding of each other, and their social needs may be almost the same. As one of them stated:

“I have the experiences of being a part of social groups. As group members, all of us were working together in one place on one project, but I always realized that their relationship was too strong among them while their relationship with me was normal even with some of them I have just hi, and bye. In short, the majority of hearing people are not interested in having relationship with hearing disabled people”. [Key respondent]

Regarding some difficulties in building healthy relationships faced by females, one of the female participants mentioned:

“I have a good relationship with my family, friends, and colleagues who are hearing disabled. But for having good relationships with friends, and colleagues without hearing loss and people in society I have tried a lot to be connected, but in society, I am still alone. The reason is that I am a female who has been always told by her mother to keep away from society. This is not because she may feel the shame of having a daughter with disability but maybe she was afraid of any bad event to happen to me as a mute and hearing disabled child. Maybe because of such thoughts of my mother I am still scared and cannot trust anyone apart from my relatives and colleagues”. [Key respondent]

Thus, the second identified theme for love and belonging needs was a sense of belonging. According to the findings, this population need more love from family members especially spouses, colleagues, peers, and friends. It has been noted that the fulfilment of this need gives them a sense of closeness, peace of mind, security, importance, and respect.

DISCUSSION

This part of the study discusses the findings of this research guided by the themes mentioned by the study group.

Social Support from Family Members and People in The Surroundings

Positive society attitudes and social support are two sub-themes under this theme. The study found that there are participants who have received commendable support from society while some have been neglected and discouraged. Social support is essential for every individual in the society including people with hearing loss. They highlighted that social support creates a positive role in the minds and behavior of people with hearing loss. Brewer et. al. (2011) has mentioned that people with hearing loss normally depend on their family support and that is crucial to them.

Support from family and friends is very much significant in the development of people with disabilities (Mill, Mayes & McConnell, 2010; Jackson & Turnbull, 2004; Schalock, Verdugo, & Braddock, 2002) and these people are able to provide them with strength and power to go ahead.

However, in Afghan society, people with hearing disabilities are may be mocked and banned from attending public events. The reason is that they do not receive support, love, value, respect, and encouragement from society, sometimes even not from friends, and colleagues. They usually have the feeling of not being accepted by people in the surrounding (Pajhwok, 2012). Such negative thinking could have influenced their parents as well, or they may lack sufficient information in this regard. Besides, some parents in Afghanistan have the opinion that they do not need to invest in people with hearing loss because they could not yield a better fortune for them in future. Beazley and Moore (2013) have commented that one of the common issues for parents with children who were born with hearing loss or having children who at an early age acquired hearing loss is the poor development of language and communication. Although hearing aids do much for some of these groups to make spoken language accessible, while for others access to spoken language becomes or remain difficult. The degree of hearing loss and communication ability of a child requires special efforts by the family members to communicate with the infant.

Parents are the most encouraging factors in improving learning in their children, because they are familiar with sign language, and they know how to

communicate with their children, and they are well aware of their child needs, and characteristics. Family activities that encourage early learning, homework supervision and reading assistance have a positive effect on the academic success of the learners with hearing disabilities.

Enabling Education Network, an NGO has shared a story of a father in Afghanistan. This story also show that having good friends is the biggest support for becoming and being confident and for having a good quality of life. This finding is in line with studies carried out by McAbee, Drasgow, and Lowrey (2017) and Moreno and Mari-Klose (2013). According to them, having good friends and receiving sufficient support, especially among friends who are also having hearing loss, may improve the quality of life of people with hearing loss. The reasons are their deeper trust and understanding, sharing similar cultures, having the same language, and making them feel valued (Nikolarazi and Hadjidakou, 2006).

Sense of Belonging

The participants believe that sense of belonging is creating a healthy relationship with others, to love others, and to get loved by others. Aruma and Hanachor (2017) have mentioned that having a feeling that certain people could support them always is a feeling of love and belonging which boosts peoples' confidence in decision-making. That's why it becomes a crucial requirement for human beings (Ellis, 2013). It was interesting to the researcher that the majority of people with hearing disability showed interest to marry those who are hearing clearly, but unfortunately, they have not been accepted most of the time as a potential partner. Mosier (1999) has mentioned that people with hearing disability could not get along well with hearing-sound individuals because both cannot interact well, which in turn can lead to unsuccessful marriage life if they got married anyhow (Mosier, 1999).

Parent-children relationship is a natural relationship. However, in all kinds of relationships which people create by himself/herself, marriage is the closest and strongest one. That's why it is believed that marriage has a greater potential in creating confidence, happiness, and peace of mind to couples (De Veirman, Haage, & Vikstrom, 2016). Fay (1898) and De Veirman, Haage, and Vikstrom (2016) have mentioned that people with hearing disability prefer to marry with people with hearing disability themselves. According to McIntosh (1995), it is estimated that 90% of all mixed deaf-hearing marriages end up with divorce (Mosier, 1999).

On the other hand, Vikström, Haage, and Lundevaller (2020) study revealed that

men and women with disabilities are reluctant to marry each other. They also mentioned that disability significantly impeded people's marriage prospects as a possible consequence of social marginalization in society. Packer (2017) states that this is because of the inability to communicate and refers to the secrets of successful marriage which are according to her communication, sharing feelings, and living by them. She further mentions that a British study involving over 1500 people with hearing loss with an age of 55 years and above revealed that almost half of them (44%) failed in maintaining a good and healthy relationship with their family and peers because they cannot hear properly (Packer, 2017).

As mentioned above participants agreed that a healthy relationship is a social need for every human being. A book entitled *Triumphs of Experience* (2012) shows that happiness and health are results of having good and healthy relationships with closed ones. They are not the result of having a good amount of money. People who are more socially related to their families, friends, or communities are happier, physically healthier than those who are less connected (Edwards, et al., 2016).

Based on the latter, it seems having a healthy relationship is a survival need for a human being. Healthy relationship stands for respecting the partner, his/her wishes, thoughts, and appearances, supporting him/her, having trust in him/her, seeking compromises if a disagreement takes place as it is natural since everyone does not think the same, and giving the needed space to each other (Roffey, 2017). But the greatest challenge for people with hearing loss in building a good and healthy relationship is their limited communication capacity which is the essential pillar among all mentioned indicators.

CONCLUSION

People with hearing loss need to receive social support from family members and friends to gain a sense of belonging. Fulfilment of this need would help them feel more successful, boost their self-esteem, develop emotional and social well-being, and reduce the feeling of being unwanted and lonely. People with hearing loss may be faced with constant challenges from within their family circle as well as from the outside world. With proper support from all quarters, these obstacles can be a positive challenge that would encourage the hearing disabled to be more resilient and fearless in the face of difficulties.

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Effectiveness of Caregiver Education for Prevention of Shoulder Pain in Acute Stroke Survivors: A Randomised Controlled Trial

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ABSTRACT

Purpose: *This study aimed to determine the effectiveness of caregiver education to prevent or reduce hemiplegic shoulder pain, a complication following stroke that adversely affects functional outcomes and prolongs rehabilitation.*

Method: *The study was a randomised controlled trial involving acute stroke survivors in the hospital and their primary caregivers. The participants were conveniently selected and randomly allocated to the experimental (n = 20) and control groups (n = 20) using block randomisation. The stroke survivors of both the study groups received conventional therapy. In the experimental group, caregivers participated in three individual sessions of the education programme for shoulder care, which comprised provision of information, demonstration and training. The outcome measures at pre-assessment were the Visual Analogue Scale (VAS) for shoulder pain and the Fugyl-Meyer Assessment for Upper Extremity for Motor Recovery. Caregiver feedback scores were obtained following the intervention. The VAS scores were obtained at 30 days following intervention and 30 days following post-assessment (follow-up assessment) through the posted envelopes. Mann-Whitney U test and Chi-square test were used for statistical analysis.*

Results: *There was no significant difference between the groups on VAS at follow-up assessment. The number of stroke survivors reporting “no pain” increased by 29% in the experimental group and decreased by 6% in the control*

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group. Caregiver feedback scores were higher in the experimental group than in the control group ($P < 0.001$).

Conclusion: This study indicates that educating caregivers on shoulder care during acute management at the hospital, improves their confidence in handling and positioning the stroke survivor after discharge and could reduce hemiplegic shoulder pain.

Key words: stroke, hemiplegic shoulder pain, subluxation, DEDICT, caregiver education

INTRODUCTION

Stroke is one of the major health problems in India (Banerjee, Mukherjee & Sarkhel, 2001). Post-stroke shoulder pain or hemiplegic shoulder pain (HSP) is a common complication following stroke (Jespersen, Jorgensen, Nakayama & Olsen, 1995). It develops as early as in the second week following stroke (Chantraine, Baribeault, Uebelhart & Gremion, 1999), and has detrimental influences on the rehabilitation process and outcomes (Rizk, Christopher, Pinals, Salazar & Higgins, 1984; Roosink, Geurts & Ijzerman, 2010). Poor handling and improper positioning of the affected upper limb following stroke is reported to be a causative factor for HSP (Jensen, 1980). It is therefore crucial to support and protect the involved shoulder joint (Viana, Pereira, Mehta, Miller & Teasell, 2012), especially during the initial acute, flaccid phase following the stroke event (Andersen, 1985; Gamble et al, 2002). Studies have shown that training the rehabilitation team in proper handling of the affected upper limb reduces HSP (Jones, Carr, Newham & Wilson-Barnett, 1998; Forster, 1999; Jones, Tilling, Wilson-Barnett, Newham & Wolfe, 2005). It is suggested that caregiver education could also be helpful (Zeferino & Aycock, 2010). This would be beneficial in India, where caregivers play a crucial role in the medical care and rehabilitation of stroke survivors.

There are very few stroke units in the country, and these are mostly located in urban areas (Pandian & Sudhan, 2013). Many hospitals do not have an adequate number of trained nurses (Yasmeen, 2014) and rehabilitation professionals to provide comprehensive care. Due to this, caregivers are often involved in the management of the stroke survivors during their hospital stay. Following discharge, as rehabilitation services are often inaccessible and unaffordable (Kamalakaran et al, 2016), caregivers are involved in self-care and therapy of stroke survivors at their homes. Thus, caregiver education could be very helpful to prevent or reduce hemiplegic shoulder pain.

Objective

In India, the prevalence of HSP is reportedly around 47.7% (Joy et al, 2012). This suggests that hemiplegic shoulder pain is a significant concern that needs to be addressed for better rehabilitation outcomes. Currently, there is limited evidence on this aspect of stroke rehabilitation in the Indian context. Innovative education programmes are recommended to meet rehabilitation needs of this population (Kamalakaran et al, 2016). Therefore, the present study aimed to determine the efficacy of a caregiver education programme to prevent or reduce HSP.

METHOD

Design

The study design was a randomised controlled trial with an experimental and control group.

Setting

The study was conducted in two tertiary care hospitals in Udupi district of Karnataka State, India.

Sample

The study participants were acute stroke survivors and their primary caregivers. Participants were selected conveniently according to the selection criteria.

Persons admitted for management of first episode of stroke, medically stable, conscious and with National Institute of Health Stroke Scale (NIHSS) scores less than 14, indicating mild to moderate stroke, were included in the study (Kasner, 2006).

Persons who had been more than five days after stroke at the time of referral, with stroke-related language impairments and unilateral neglect, prior history of hemiplegia and shoulder trauma, were excluded. Stroke survivors with NIHSS scores greater than 14, indicating severe stroke requiring long-term care (Brott et al, 1989) were also excluded.

For inclusion, caregivers of the acute-stroke survivors selected for the study were required to have adequate comprehension and communication abilities. Caregivers with any psychiatric comorbidity were excluded.

Informed consent was taken from both the stroke survivors and their caregivers.

Procedure

The sample size was estimated using the formula, $n = 2 (Z_{1-\alpha/2} + Z_{1-\beta})^2 \sigma^2 \div d^2$, where $Z_{1-\alpha/2} = 1.96$ at $\alpha = 5\%$ (level of significance), $Z_{1-\beta} = 0.84$ at $\beta = 20\%$ (power), $\sigma = 1.7$ (computed from $10/6$, where 10 denotes the range of the value and 6 denotes the standard deviation assuming the data will follow normal distribution of $3 \pm$ SD) and $d=2$ which was the clinically significant difference on Visual Analogue Scale (VAS) for pain set by the investigators. A sample size of 11 per group was estimated and it was increased by 20% since non-parametric tests were expected by which a sample size of 15 per group was calculated. Since a dropout rate of 20% was expected, the final sample size was determined to be 20 per group.

To ensure equal number of participants in the control and experimental groups, block method of randomisation was used. Considering a block size of four with 10 blocks, a random sequence of codes was generated using computer method. Each code was sealed in an opaque envelope prior to study commencement. Blinding could not be done in this study due to practical constraints. Pre-assessment was done on the fifth day following stroke, using the outcome measures selected for the study. Stroke survivors of both the study groups received conventional therapy. In the experimental group, caregivers participated in the education programme for shoulder care. Following provision of intervention, caregiver feedback was obtained. Post-assessment was done 30 days after intervention and the follow-up assessment was done 30 days following post-assessment. The post- and follow-up assessments were done through telephone and by post.

Outcome Measures

The Visual Analogue Scale (VAS) was used to assess the shoulder pain on a scale ranging from 0 to 10, where 0 indicates "No pain" and 10 indicates "Very severe pain" (Price et al, 1983). Motor recovery of the affected upper limb was assessed with the Fugyl-Meyer Assessment for Upper Extremity (Fugyl-Meyer, Jaasko, Leyman, Olsson & Steglind, 1975). Both these measures were used at pre-assessment (fifth day following stroke). The stroke survivors and caregivers were provided stamped envelopes containing the VAS at discharge. On the scheduled day of post-assessment and follow-up assessment, the investigator instructed the caregivers and stroke survivors, over the phone, to mark the pain scores on the VAS and to post their responses to the investigator.

Caregiver feedback was obtained after intervention using a 5-item ordinal scale. Each item was scored ranging from 1 (lowest score) to 5 (highest score). The items included: 1) satisfaction with information provided about stroke, 2) satisfaction with information about complications following the stroke, especially shoulder pain, 3) satisfaction with instruction and training about handling and positioning, 4) confidence gained in handling and positioning the stroke survivor, and 5) overall satisfaction with the education programme. The average score of the 5 items was computed.

Intervention

In both the study groups, the stroke survivors received conventional therapy which included positioning, facilitation of motor recovery and shoulder sling or cuff usage with general instructions. In the experimental group, the caregivers participated in the education programme. The caregiver education programme was developed according to the World Health Organisation guidelines (Gorske, 2011) and a direct skill instructional model called DEDICT (Thomas, 2007). The programme involved three individual or one-to-one sessions over three days. The first session was conducted in the local language, using an illustrated educational handbook with information about stroke and its complications, shoulder pain and subluxation, importance of correct handling and positioning, and proper sling usage. Handouts were provided to the caregivers during the session. The second session included practical demonstrations on proper positioning, handling and transfers of stroke survivors, followed by practice for caregivers. The third session included recall and review for the caregivers, followed by feedback and queries. Each session took 30 to 60 minutes. When possible, stroke survivors were also involved in all the sessions.

Data Analysis

Data analysis was done using SPSS 17.0 Version. The level of significance was $P < 0.05$. Comparison of the two groups was done with Mann-Whitney U test and Chi-square, for continuous and categorical variables respectively. Pearson's correlation was done to study the association of Fugyl-Meyer Assessment for Upper Extremity, with VAS at pre-assessment. VAS scores at post- and follow-up assessments were analysed descriptively.

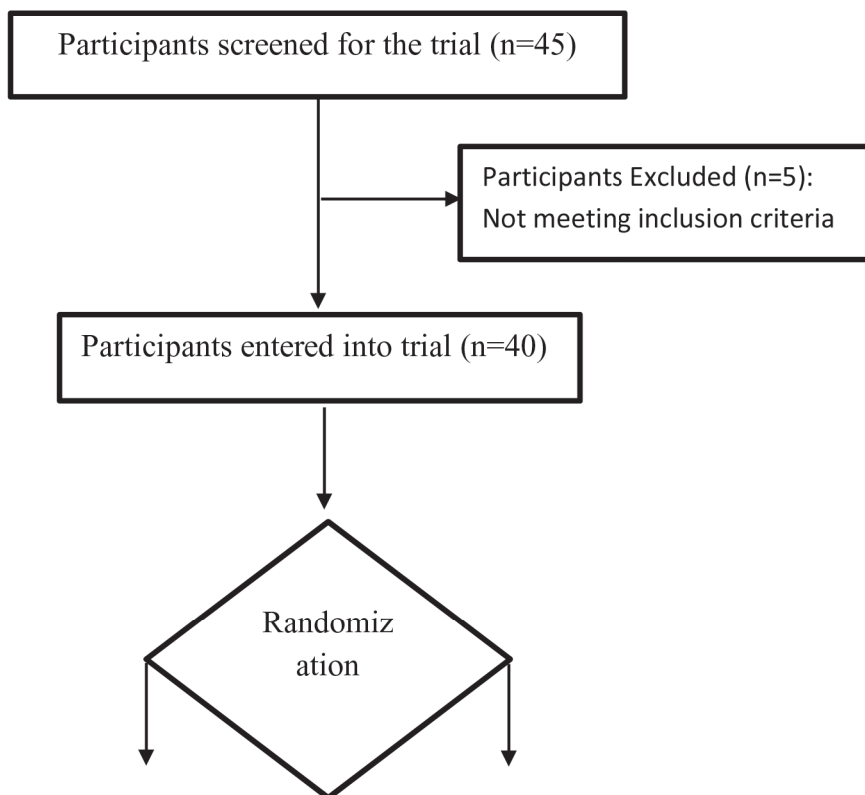
Ethics Approval

Approval of the Institutional Ethical Committee was obtained (IEC 400/2015).

RESULTS

Forty stroke survivors (20 in the control group and 20 in the experimental group) and their caregivers participated in this study. Figure 1 displays the flow of the participants during the study. The post-assessment had 35 participants (17 in the control group and 18 in the experimental group) and follow-up assessment had 33 participants (16 in the control group and 17 in the experimental group) due to drop-outs. Table 1 shows the sociodemographic and clinical characteristics of stroke survivors and Table 2 shows the sociodemographic characteristics of the caregivers.

Figure 1: CONSORT Diagram showing the Flow of Clients through the Trial



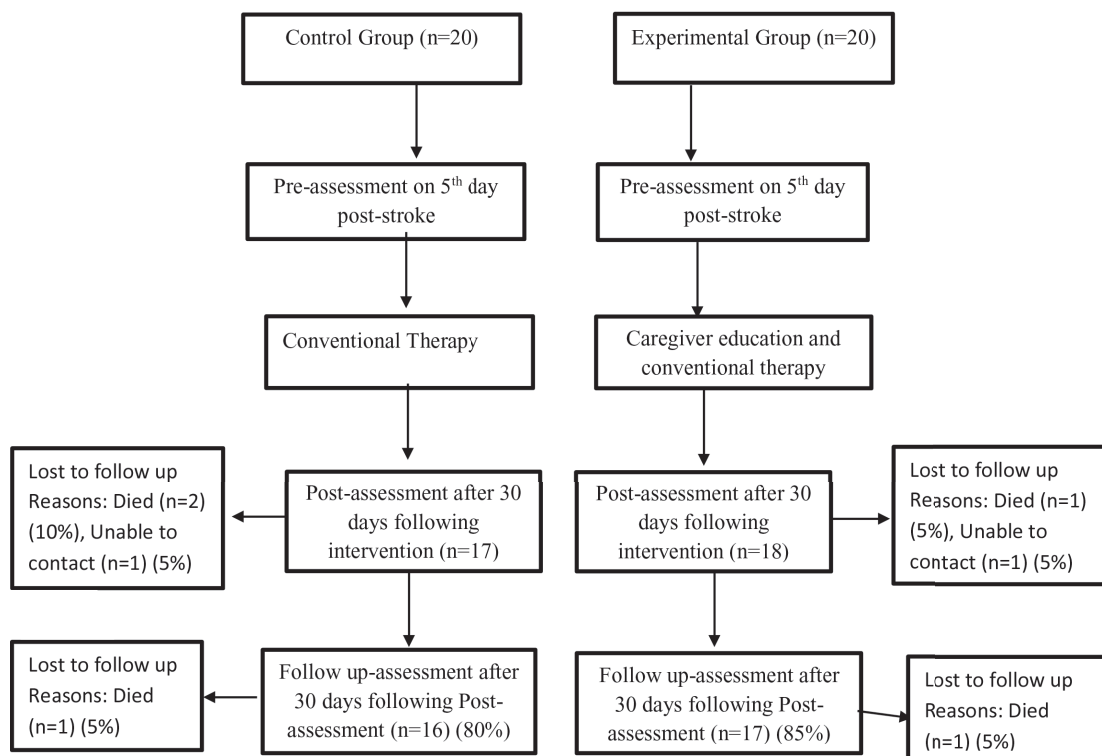


Table 1: Sociodemographic and Clinical Characteristics of Stroke Survivors

Characteristics	Groups		
	Experimental (N=20)	Control (N=20)	
Gender	Male	12 (60%)	9 (45%)
	Female	8 (40%)	11 (55%)
Education	None	5 (25%)	5 (25%)
	Up to tenth grade	10 (50%)	13 (65%)
	Diploma/Graduate	5 (25%)	2 (10%)
Occupational status	Working	17 (85%)	20 (100%)
	Retired	3 (15%)	0 (0%)
Side of lesion	Left	10 (50%)	10 (50%)
	Right	10 (50%)	10 (50%)

Chi-square test indicated no statistically significant difference between the stroke survivors of the study groups with respect to gender ($P = 0.342$), education ($P = 0.432$) and occupation ($P = 0.72$). Similarly, Chi-square test suggests no statistically significant difference between the caregivers of the study groups with respect to

gender ($P = 1.00$), education ($P = 0.442$), occupation ($P = 0.35$) and socioeconomic status ($P = 0.71$). Table 2 shows an important finding that caregivers in both the study groups included more women and parents who were involved in productive work.

Table 2: Sociodemographic Characteristics of Caregivers

Characteristics		Groups	
		Experimental (N=20)	Control (N=20)
Gender	Male	7 (35%)	7 (35%)
	Female	13 (65%)	13 (65%)
Relation with stroke survivor	Spouse	6 (30%)	4 (20%)
	Parent	10 (50%)	8 (40%)
	Child	2 (10%)	7 (35%)
	Others	2 (10%)	1 (5%)
Education	Up to tenth grade	4 (20%)	3 (15%)
	Higher secondary	7 (35%)	11 (55%)
	Diploma/Graduate	9 (45%)	6 (30%)
Occupational status	None/ Retired	0 (0%)	4 (20%)
	Working	20 (100%)	16 (80%)
Socioeconomic status	Low	4 (20%)	6 (30%)
	Medium	8 (40%)	8 (40%)
	High	8 (40%)	6 (30%)

Table 3 shows the results of the Mann-Whitney U test. There was no significant difference between the groups for stroke survivors' age, caregivers' age, duration of hospitalisation, NIHSS scores and pain scores. However, the control group had significantly higher Fugyl-Meyer motor function scores than the experimental group. Pearson's correlation coefficient indicated significant association of Fugyl-Meyer motor function scores and pain scores at pre-assessment, Pearson's $r = -.41$, $p = 0.008$. As seen in Table 3, the VAS scores of the two groups were similar at post-assessment and follow-up assessment.

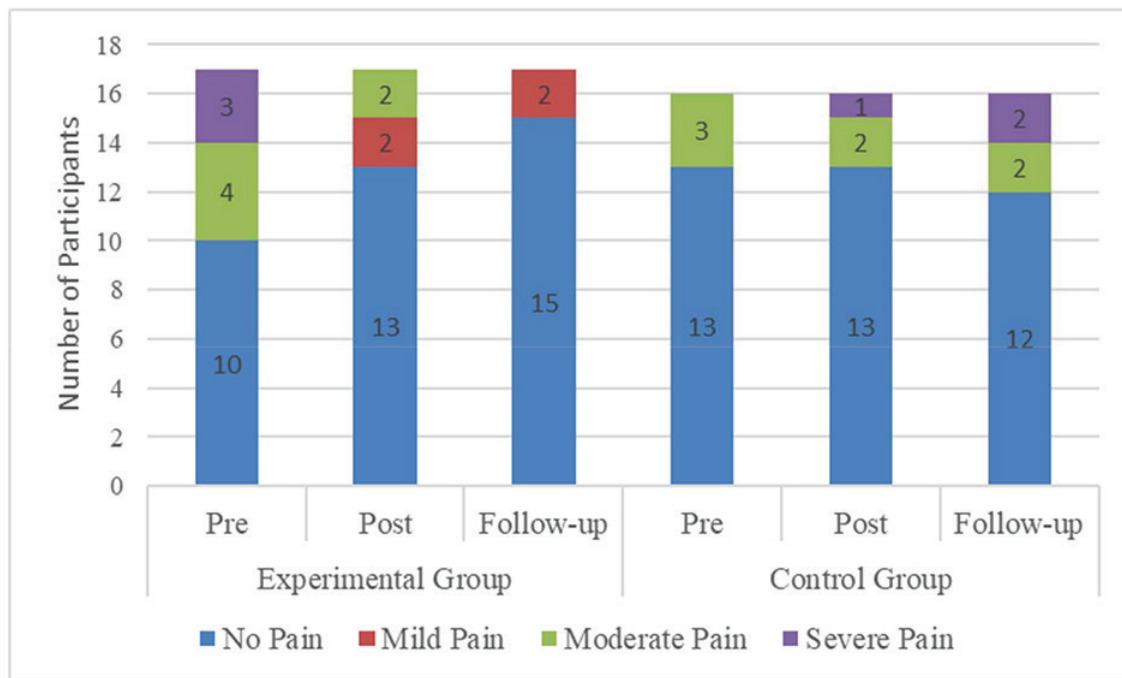
Table 3: Comparison of Participant Characteristics between Study Groups

Variables	Groups		'P' value
	Experimental Median(IQR)	Control Median(IQR)	
Client age (n = 40)	59.5(50-71)	59(46-64)	0.357
Caregiver age (n = 40)	32.5(26-49)	38(31-55)	0.180
Duration of hospitalisation(n = 40)	8(7-10)	7(7-9)	0.350
NIHSS scores (n = 40)	8(0-12)	4(0-15)	0.074
Fugyl-Meyer motor function (n = 40)	0(0-21)	36.5(0-65)	0.042*
Caregiver feedback (n = 40)	4.9(4.45-5)	2.4(1.65-3)	0.000*
Visual Analogue Scale			
Pre-assessment (n = 40)	1.5(0-7)	0(0-3)	0.172
Post-assessment (n = 35)	0(0-4)	0(0-7)	0.929
Follow-up assessment (n = 33)	0(0-2)	0(0-8)	0.581

*level of significance at $P < 0.05$; IQR- Interquartile Range

Figure 2 shows the VAS pain scores of the participants of the two groups who completed the pre-, post- and follow-up assessments. In the experimental group of 17 participants, the number of stroke survivors with 'no pain' increased from 10 (59 %) at pre-assessment to 15 (88 %) at follow-up. In the control group of 16 participants, the number of participants with 'no pain' reduced from 13 (81%) to 12 (75%). Also, the number of stroke survivors reporting "moderate to severe pain" decreased in the experimental group and increased in the control group during the follow-up assessment. Caregiver feedback scores were significantly higher in the experimental group than the control group as seen in Table 3.

Figure 2: VAS Pain Scores in the Study Groups



DISCUSSION

The experimental and control groups in the present study were similar in baseline characteristics, except for Fugyl-Meyer motor function scores that indicated moderate level of impairment in the control group and severe level of impairment in the experimental group (Woytowicz et al, 2017). At follow-up assessment, although the pain scores were similar in both the groups, the number of stroke survivors reporting “no pain” increased in the experimental group. In contrast, although the control group had better motor function scores at baseline, at follow-up the number of people with “no pain” decreased while those with “severe pain” increased. This finding was surprising as hemiplegic shoulder pain has been found to correlate with poor arm motor function and range of motion restriction in the acute and chronic stage of hemiplegia, and also with spasticity in the chronic stage (Pong et al, 2009; Pong et al, 2012) which is also supported by significant association between Fugyl-Meyer motor function scores and VAS pain scores at pre-assessment in the present study. Thus, a possible explanation is that stroke survivors in the control group with moderate level of upper limb impairment may have developed HSP due to abnormal humeral and scapular

kinematics caused by weakness and spasticity of the rotator cuff and scapular muscles, incorrect exercises, especially overstretching or overloading and handling (Lindgren, Jonsson, Norrving & Lindgren, 2007; Pong et al, 2009). The follow-up assessment was done around two months after stroke during which time stroke survivors commonly develop shoulder subluxation (Suethanapornkul et al, 2008), spasticity (Pong et al, 2009) and range of motion restriction (Pong et al, 2012). Rotator cuff injuries, tendinosis of the long head of the biceps tendon and supraspinatus are the common findings associated with HSP in the chronic stages. This could hinder motor and functional recovery of the hemiplegic arm (Rizk et al., 1984; Roosink et al., 2010). In view of these findings, future clinical trials may have to consider using stratified randomisation based on levels of upper limb motor impairment.

Thus, as recommended by earlier studies, prevention of shoulder pain should be an essential component of acute stroke care, especially for those with low general health status and poor arm function at baseline (Turner-Stokes & Jackson, 2002; Pong et al, 2012). In addition, stroke survivors with better arm motor control at baseline would also benefit from education programmes during acute care to prevent shoulder pain and support further motor recovery.

The caregiver feedback scores were higher in the experimental group than in the control group. Thus, caregivers were satisfied with the programme as it improved their confidence about shoulder care. This finding further supports the usefulness of the caregiver education programme.

The caregiver education programme in the present study was adapted from the DEDICT model (Thomas, 2007), that involves demonstration, explanation, second demonstration, imitation, correction/coaching and trials. Though this model was originally developed for physical education, it was used in this programme for educating and training caregivers. Compared to home programmes through handouts or verbal instructions at discharge, the present study suggests that a discharge programme involving education and training probably facilitates better generalisation or application of home programmes following discharge to effectively reduce shoulder pain. This could be due to better understanding about the shoulder joint, mechanism of the injury, complications such as shoulder hand syndrome and its prevention. Instead of merely explaining dos and don'ts, the caregiver education programme helped the caregivers in understanding the rationale of treatment and gave them a sense of control. The practice session, recall

and review, followed by caregiver feedback and queries, facilitated confidence in the caregivers about shoulder care of stroke survivors.

Limitations and Recommendations

The present study intended to have follow-up assessments for the stroke survivors' motor recovery and functional independence, at one month and two months following discharge. The study was carried out at a super-specialty hospital that caters to clients from neighboring districts and states. The duration of hospital stay is usually short (around 7 - 10 days) and stroke survivors are discharged once they are medically stable. Following discharge, most of the stroke survivors tend to follow-up at hospitals or clinics near their homes. Thus, follow-up at this tertiary hospital is usually challenging. Cognizant of this, in the present study the follow-up assessments for VAS scores were obtained through post but Fugyl-Meyer motor function assessment could not be done. Due to the short hospital stay and poor follow-up, detailed assessments could not be done including clinical assessments for stroke survivors' motor and functional recovery, factors associated with HSP such as subluxation, spasticity, other conditions such as thalamic pain, and objective assessments such as radiography, sonography, etc. The impact of these on study findings cannot be ruled out. Due to practical constraints and challenges in participant recruitment, stratification and blinding could not be done. During sample size estimation, in the absence of any literature based on experience, the researchers considered a modest change of 2 points in the VAS scores as the value for clinical significant difference (d) in the formula. This may explain the sample size computed for the study. The use of other interventions such as medications to reduce pain or spasticity following discharge could not be ascertained. In view of these limitations, the study findings need to be generalised with caution.

Thus, the present study could be considered a preliminary study that demonstrates the potential and feasibility of a caregiver education programme in acute care set-ups, to reduce HSP in resource-constrained settings. Considering the implications of shoulder pain to outcomes of stroke rehabilitation, further research on this is warranted. Multi-centric randomised controlled trials with blinding, stratification based on upper extremity motor function scores, larger samples and longer follow-ups with direct, standardised, objective clinical and functional outcome measures are thus recommended.

CONCLUSION

The study demonstrates that educating caregivers about shoulder care during acute management of stroke survivors could reduce hemiplegic shoulder pain.

Implications

The study findings suggest that caregiver education in the acute phase, during hospital stay, of the stroke survivors could reduce HSP. The caregiver education programme developed in this study is practical, feasible and cost-effective. It can be easily integrated with conventional therapy for stroke, even during the short duration of hospitalisation. It can be conducted in groups and can be provided by any healthcare professional. As in the present study, caregivers of stroke survivors are often working people, women and parents. With limited access to and affordability of rehabilitation services in India, innovative and person-centric education programmes (Kamalakannan et al, 2016), as of the present study, are essential to reduce caregiver burden. It will also help increase stroke survivors' participation in daily activities, adherence to long-term rehabilitation and improve treatment outcomes.

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Evolution from Negative Identity to Affirmation of 'Disability Identity': Life story of a Woman with Spina Bifida in India

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ABSTRACT

Purpose: *This paper is part of a research study that explored the lived experiences of adults with physical disability in Delhi, India. It traces the evolution of a positive outlook towards disability in a young woman living with spina bifida.*

Method: *This paper is part of a larger study, and is one of the twelve narrative accounts of adults with physical disability, who had been selected to be part of the study using purposive sampling. The study adopted a life story approach wherein the participant talked about their life events in a chronological order. It is believed that stories constitute the psychological realities, including identity, and identity is expressed in sociocultural relations through talk. This paper is the life story of one woman with spina bifida and it recounts her journey depicting the dynamic nature of identity construction. Her life story gives rich insights in terms of personal and social experiences that enabled the researcher to explore the complexities in identity construction. A pseudonym, Ashima, has been used to maintain confidentiality.*

Results: *By describing her childhood experiences, medical journey, relationships, and marriage, the participant was able to make sense of the events leading up to the emergence of a positive disability identity. The daily lived realities of exclusion had instilled a sense of negativity in her but she began to affirm the disability identity after contact with disability groups. The positive role of the family was an additional factor in the participant's acceptance of her disability identity.*

Conclusion: *The paper presents the emergence of a positive identity by challenging the traditional approaches and oppressive social constructions of disability. It underscores the importance of voice, agency and the celebration*

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of disability identity, and paves the way for future researchers to listen to the insider's perspective in order to create a culture of valuing differences.

Key words: *disability, disability identity, life story, lived experiences*

INTRODUCTION

"This chair is not my wheelchair, it's my will chair, means full of will power and I feel good. This helps me in moving so I take it positively"- Ashima (2018).

Ashima's life story depicts the journey of her evolution from negativity, due to societal ascriptions to her impairment, to the proud affirmation of her disability identity. It reveals how she navigated a path through the experiences of living with a physical disability, and finally embraced her identity in a collective context of people with disabilities. Her life story clearly demonstrates that coming to terms with a disability identity was not smooth sailing but a process in itself.

Disability Identity Development and the Life Story Approach

Historically, disability has been seen as a medical tragedy that situates the problem within the individuals considering negative self-identity as an outcome of physical impairment, and the onus lies with them to correct or normalise their problem (Shakespeare, 1996). For a long time, people with disabilities have struggled with a bodily identity that was boxed in a medical model and thus reduced it to an abnormality (Zitzelsberger, 2005). This model has invalidated the bodies that do not conform to the norm, and such impaired bodies were seen as deviant, flawed and inferior (Campbell, 2008).

With the emergence of disability activism, the social model was proposed which espouses the role of disabling barriers in the environment as a root cause of oppression and disability (Swain & French, 2000). The two approaches can be understood by viewing identity as a narrative where focus is on the stories that people tell about themselves. As Giddens (1991) said, 'Self-identity is not a distinctive trait, or even a collection of traits possessed by the individual. It is the self as reflexively understood by the person in terms of her or his biography'.

To support what Giddens has asserted, it is relevant to mention the significance of the life story approach as a method in exploring identity. McAdams (1990) pointed out that identity should be seen as an autobiography project which situates a person in the world, integrates a life in time, and provides meaning

and purpose. Furthermore, stories constitute the psychological reality including identity (McGannon & Smith, 2015). For researchers adopting the narrative research tradition, identity is not something inside the individuals but it is performed through the stories that they share (Frank, 2010). Here, the participant's life story portrays the emergence of a positive identity and empowering outlook. This further emphasises that recounting the life story is empowering, which Meininger (2006) also found in research on people with intellectual disabilities. Besides, when people share their stories of struggle and resilience against experiences of discrimination and exclusion, the life story approach contributes to a better understanding of their journey, thus adding up to a profound sense of self and identity (Atkinson, 2005). The life story method offers the story teller an opportunity to recall her/his life and trace the events that occurred at various periods. The method examines "the insider's perspective of the individuals; how they understand, interpret, and define meaning of the world around them" (Faraday & Plummer, 1979). In a similar vein, Cole (2001) expressed that by giving importance on the subjective meanings and perspectives that individuals ascribe to their experiences, the life story approach gives voice to the experiences of those people whose voices remain suppressed or unheard. Given the advantages that the life story approach offers, it qualifies as a suitable method for the study.

Identity construction task is a composite one that does not take place in isolation; instead, it is expressed in the influence of socio-cultural interactions (Bruner, 1990). Disability as a negative identity emerges out of social processes that view impairment as the sole criterion of analysis (Olkin, 1999). People with disabilities may stoically accept such negative identities and take it as an individual loss. These individuals take the blame on self, and experience grief and loss personally (Shakespeare, 1996). However, research claims that there are ways in which individuals from stigmatised groups tend to manage stigma and thus try to improve their self-concept (Tajfel & Turner, 1979). There may be instances where these individuals manage disability by passing off as normal or by hiding their disability identity (Goffman, 1963). Shakespeare (1996) termed all these processes of identity management as psychologically and socially unhealthy. According to him, all these processes involve a component of denial or failure to accept disability identity; and doing this could result in a temporary identity that might affect an individual psychologically. The emergence of disability as a positive identity is a process where individuals living with impairment resist the negative ascriptions that society has attached to them, thus asserting that the problem resides in the social barriers. This also means that they reject subjection and move

into positive self-identification. This can be a self-awakening process or can take place in a collective context (Shakespeare, 1996). For people with disabilities, disability identity entails growing up with a positive sense of self, and a feeling of connection to, and affinity or solidarity with, other members of the disability community (Scotch, 1988; Gill, 1997; Olkin & Pledger, 2003).

The advent of the disability movement has led to a slow cultural shift towards a social construction of disability that identifies the prevalent nature and extent of disability oppression and offers a new lens of viewing disability as diversity to be affirmed and celebrated (Mackelprang & Salsgiver, 1999). From the disability studies perspective, identity and self tend to be viewed through an interpretation of oppressive social relations with the emphasis on changing society and empowering people with disability; for example, Barnes' analysis (1990) of the socialisation and identity formation of young people with disability. The disability studies proponents contribute to a new approach that is focused on the person's agency to counteract the challenges of oppression.

RATIONALE OF THE STUDY

Historically people with disabilities have been subjected to oppression, exclusion and discrimination amidst the stereotypical attitudes of the societies that view them as flawed and undesirable beings (Rioux, 2001; Chandler & Swart, 2014). Much of the documented research on people with disabilities focused on the quantitative aspects, thus making their experiential accounts invisible and eventually furthering the perpetuation of stereotypical attitudes of society towards them. In this regard Oliver (2006) maintained that a change in research process is a must in order to alter the prevalence of such stereotypical attitudes towards people with disabilities. This calls for listening to the perspectives of individuals with disabilities. Here it is pertinent to mention Gerber (2006) who asserted that the voices of people with disabilities are critical in defining the discussions around disability.

Thus the present study is premised on listening to the voices of people with disabilities as it is believed that their voices are crucial in sharing their experiential accounts of life with a disability. By having their experiential insights of living with disability the study attempts to fill the gap i.e. seeing the people with disabilities as passive beings with no voices of their own.

METHOD

Study Design

Gaining perspectives and experiences of those whose voices have been suppressed for long and are not heard through traditional academic discourse, lies at the heart of qualitative research (Booth, 1996). The life story approach not only caters to internalised oppression but also provides space for empowerment by bringing the diverse realities of the marginalised to the light (Goodley, 2000). Life story is a form of narrative research where lives of individuals are studied by conducting interviews with them in order to gain a detailed insight of their lives (Creswell, 2002). By hearing their stories, the study believes in the philosophy that these individuals have the right to express themselves, and their voices need to be heard. Life story method allows the researcher to see the person's life in all its complexity and all the processes that have gone into making the individual who he or she is now (Chamberlayne et al, 2000). Keeping in mind the above belief, the life story method serves as the best choice in examining the experiences of adults with physical disability who are hardly represented in Indian research. In this paper, the life story of Ashima depicts the experience of living with a physical disability in India and illustrates how she developed as an individual capable of affirming her disability identity with pride.

Sampling

Twelve participants were selected through a purposive sampling strategy meant to select "information rich cases" so as to get detailed insights about the phenomenon in question (Merriam, 2009). Ashima's story was selected from among the twelve participants' stories, as her story captured the essence of personal and social experiences that explored the complexities involved in identity construction. Ashima's life story depicted the dynamic nature of identity construction. From being trapped in a negative identity due to the experiences of living with disability, she developed as a positive individual embracing her disability identity in the present context.

She takes pride in who she is and has found the experience of living with disability as a positive one and she takes it as her strength. This positive aspect wasn't observed in the life stories of the other eleven participants as they were ambivalent when it comes to accepting disability identity, hence her story of resilience and positivity is presented through this paper.

Study Participant

Ashima, a 30-year-old income tax clerk, is a married woman. The researcher met her at one of the events of the organization (X) working for persons with disabilities, where people with all kinds of disabilities socialise and seek support. Ashima had been associated with this organisation for more than a year.

Data Collection

The sessions began by giving the participant an information sheet that contained details regarding the study, procedures, associated risks and benefits, and a consent form. Her consent was obtained after she had read the information sheet and agreed to participate. She was assured of anonymity, i.e., nowhere in the study would she be identified, and a pseudonym was used. She was also informed that her participation in the study was voluntary and she could withdraw from the study whenever she chose. Her approval was also sought for audio-recording of the sessions.

After obtaining the participant's consent, the focus was on building and strengthening rapport with her by conducting meetings in cafes, or seeing her at the events organised by the disability organisation. This process helped in fostering familiarity so that she could begin sharing her life story without any apprehensions. Once a relationship of trust was established, the interview sessions began. These were conducted either at her home or workplace, depending on her convenience. Light conversation on day-to-day happenings would be followed by the recounting of her life story. The participant was asked to begin her story of living with a physical disability from her childhood days and continue up to the present.

An interview guide, consisting of areas to be covered, was used to facilitate the discussion. The areas included, "Experiences related to daily life activities", "Describing experiences of social life", "Sharing experiences at the workplace", "Sharing the way you see yourself", etc. The sessions usually began with the participant talking about her life uninterruptedly, and at the end of the sessions the researcher would probe the areas that had not been covered. In this way additional details and clarifications were obtained. Follow-up sessions that were conducted involved clarification, elaboration and the use of probes to gather richer insights (Sparkes & Smith, 2014). This technique validated the narratives collected so far and helped in establishing the rigour of the research. The sessions were audio-recorded and transcribed verbatim for thematic analysis (Patton, 2002).

Ethical Considerations

The ethics clearance for the study was granted under the project code number 1811 by the Institutional Ethics Committee, Institute of Home Economics, University of Delhi.

RESULTS

Life Story of Ashima

Ashima (name changed) is a 30-year-old married and independent woman who works as a clerk in the Income Tax department. She comes across as a lively lady with a sparkle in her eyes, defying the image that society holds of disability. Her positive demeanour took years to evolve. Ashima has now emerged as an optimistic person who affirms and celebrates her identity. Her journey is presented in different phases, recounting the major challenges she faced and her emotions at the time.

Medical Journey: an Anxious Phase

Ashima was diagnosed with spina bifida when she was born. Spina bifida, one of the most common birth defects, occurs when the spinal column is split due to failed closure of the embryonic neural tube during the fourth week post-fertilisation (Fletcher & Brei, 2010; Copp et al, 2016). Individuals living with spina bifida present motor and sensory neurological deficits below the level of lesion, which hamper or reduce walking. Lack of sensation and urinary and faecal incontinence are other physical issues that happen frequently (Copp et al, 2016). Owing to the complex nature of spina bifida, the diagnosis and treatment begins at birth and through adulthood involving multiple disciplines (Fletcher & Brei, 2010).

As the impairment caused physical issues, a corrective surgery was conducted on Ashima when she was two years old. However, a few years later impairment related issues such as difficulty in walking and irregular bowel-bladder movements arose, to the distress of her parents. Despite unfavourable circumstances they persevered in trying to locate doctors wherever they were assured of better treatment. Consecutive surgeries were conducted which did not yield positive results and this worried the parents further. The medical journey continued till Ashima turned seventeen. It was a nightmare as, with each corrective treatment, her condition deteriorated instead of getting better. With no fruitful outcome and

lack of guidance by the doctors on post-operative care, the medical phase was a nerve-wracking experience according to Ashima.

"I wasn't told about post-surgery issues... that I was supposed to do physiotherapy or do these, do that as in like what to do after surgery. When during follow-up doctor was asked, then he said, 'What I have to do I did; now it's your duty how you would manage'. There was nobody to tell me. Because of medical line I had always faced difficulties."

Frustration at Home

The growing number of physical issues and poor treatment outcomes created emotional turmoil for Ashima. She would often get infuriated with her family members for paying extra attention to her. The frequent hospital visits that accompanied treatment procedures were physically and emotionally taxing. She began to question, "why me?", and was gradually slipping into depression.

"My nature was becoming weird on each new day... was getting frustrated. I was not willing to talk to anybody and when my parents took extra care of me I used to feel bad that why are they taking care of me. Why my mumma always say to me, 'you take care like this, do exercise 3-4 times, do physio...all this'. I was getting irritated, that every morning when I wake up there is new problem that comes up."

Feeling "different" at School

Being at school was not easy, as Ashima had to face bullying when other children commented about her physical condition or imitated her movements. There was a feeling of 'being different' when she was not involved in scholastic activities like the other children were. She described one incident where she was willing to be part of an event, but was denied participation due to her physical condition. Such episodes made her feel different from the rest of the children at school.

"Like I used to limp a bit, then children used to copy that, then I used to feel bad. Sometimes it used to happen that everyone was going to prayer ground but I wasn't, then I used to feel tormented. So all this was there. I was willing to do everything and they used to say that 'you can't do, you leave it, you sit down... you can't do it'. Like this, so this thing was more..... small- small things were more harrowing."

Facing Rude Stares and Curious Comments

Ashima's physical condition was eye-catching. Everywhere she went, people used to stare and pass belittling remarks. This made her acutely aware of her physical impairment. While growing up she was constantly being asked awkward questions. This was so irksome that she wanted to avoid people and usually locked herself away at home or kept her outings to the minimum. These societal attitudes engulfed her identity in negativity and she lost the confidence to face people.

"You don't get acceptance in society, and whenever I used to go out people used to ask me what has happened. I wanted to forget my problems and people just poke me to remind all this things, all that things. I couldn't face people that why they keep on asking me? Why are they irritating me? Most of the times they used to give weird gestures like no one was more helpless than us, such expressions they used to give, then after all this it became most difficult and I decided not to go anywhere and just be at home."

Losing Hope

Weakness due to her impairment and associated physical issues had increased by the time Ashima reached standard 11 in school. This led to further hospital visits where doctors advised another surgery albeit with minimal chances of improvement. Losing all hope, Ashima was in a state of shock and depression. This had a debilitating effect on her.

"Gradual weakness was imminent and when doctor was asked about the same and sought suggestion he said, 'okay, fine, will do surgery of spine where 50-50 percent chances will be there, either she will be alright or she will be bedridden.' That time such things like getting bedridden used to affect badly, so much that I used to cry-cry-cry.... troubling everyone..... I went into depression."

Phase of Emotional Stress: Questioning Self

Oppressive attitudes were weighing Ashima down. She began to view herself in a negative light. Loss of confidence and vexation at constantly being asked about her impairment led her to question, "why me?" The harsh attitudes of society caused her agony.

"That time people, too many of them used to ask... who all to answer, face their reactions, and gestures. My confidence was almost gone to face others, to prove myself to achieve something in life; I wasn't able to face anyone."

Assistive Devices as a Source of Shame

When walking seemed no longer feasible, Ashima resorted to using a stick. She was hesitant to do so because the visibility of her impairment invited questioning and stares from people. These made her feel ashamed to rely on assistive devices. However, her discomfort while walking increased to the extent that she finally had to use a wheelchair.

“When I started using a wheelchair, I felt that I shouldn’t look at anyone else, I shouldn’t face anyone; people were surprised all of a sudden that till few days back she managed to walk and what has happened now that she’s on wheelchair....questioning by people...”

Curtailing Social Participation

Stigmatising attitudes towards her impairment led to emotional trauma. Objectionable stares and questions by people were hurtful and Ashima cut back on attending social gatherings and avoided visits.

“I wasn’t able to face people... I was getting annoyed...frustration was there. I used to avoid going to marriages as there people will gather to ask what happened... what happened... what happened....and again I have to repeat the story.”

Visibility of Impairment: Impediment to building Love Relationships

Ashima’s visible physical impairment was a deterrent in attracting the opposite sex. She noticed a change in the behaviour of the opposite sex once they spotted her disability. This gave her a clue that nobody wanted to be in a relationship with her.

“When I keep on sitting, the person stares or look, like treated me like a normal person and when I started walking the behaviour actually changes. I didn’t like this though I wanted to be in a relationship, but nobody was willing to, just because of my impairment.”

Hiding of Disability: Discomfort at being Noticed

Ashima found it harrowing to be stared at and felt the need to hide her disability. She did not want people to be aware of her impairment as she wanted to be treated like everyone else.

"I wanted to hide my disability. I wasn't able to show anybody, I was anxious regarding this thing. I wanted to live a normal life from within. I used to feel that people should treat me like everyone else but it wasn't happening."

With Disability and Without Disability: a pronounced "difference"

At the time when Ashima was studying for the competitive examinations, she happened to meet a person without disability who grew close to her and they were soon in a relationship. The bubble burst when doubts crept in because of his hesitation in acknowledging her as his partner, disability and all, in front of his friends or at social gatherings. This deepened the gulf that is established by society between a person with disability and one without disability. A person with a disability is not regarded as a suitable choice for love relationships, as Ashima found.

"I was in a relationship with the able-bodied person. His friends knew where I live, what job I do, how I look.....means everything.....that where my father's shop is... everything...but they didn't know that I am disabled. Then sometimes I felt like why didn't you disclose it, then he said, 'I don't want to take opinion of others, like if they say anything negative to me or something like that then I don't want to listen that.' I felt that he had problem sharing my disability."

Getting married as a turning point

Ashima faced difficulty in love relationships and marriage prospects as nobody saw her as a potential partner. This made her feel that marriage wasn't meant for her until one day when she happened to meet Rohit (changed name), an independent man living with spine disorder, through one of the disability organizations. Meeting Rohit made her believe that she could also be loved, and there she decided to give marriage a chance. She described her marriage as one of the turning points in life as it made her strong in terms of love as she spoke about it:

The kind of negative reactions I was receiving from boys and later on relationship with the able bodied man which was heartbreaking... I began to feel that marriage wasn't happening...marriage wasn't meant for me. But when I met Rohit, the kind of confidence he gave, I thought let's give it a chance and I can say it was the best decision. It made me strong and when you have partner who is psychologically supporting so that matters... and I have one such.

Family as a Buffer against the Odds

Although Ashima was plagued by impairment-related issues and baffled by societal attitudes, it was the constant efforts of her family and siblings that kept her going. Her family urged her to participate in the wider context and feel independent. She highlighted the catalytic role of family in fostering positivity in her.

“Family was the greatest pillar, my foundation, my base was strong, that is my family. They stood by me as in to date I never felt that in family anyone has any problem in going out with me. My family supports me a lot, a lot. Then gradually I started moving out. Sister also said move out and then family members also made me understand regarding the same. They never compelled me for anything, always kept in comfort zone, and also supported my education.”

Meeting with an Accident: a Rebirth of Self

Till her first year of college, although walking with a stick, Ashima felt independent as she could drive. However the following year she met with an accident. She was lucky to escape with minor injuries but her parents were alarmed and subsequently stopped her from driving a car. This incident filled Ashima with the fear of losing her independence. Living in a society where daily social interactions had already made her feel negative, the accident increased feelings of dependence. Then one day she happened to read an article which featured a person with disability who had successfully managed to drive a car with the necessary modifications. She decided to see him and as per his suggestion was back to driving after modifications were made to her vehicle. From here began her new journey of reading about people with disabilities and, thereafter, socialising with them.

Coming in Contact with People with Disabilities: an Awakening of Self

Meeting and mingling with people with disabilities gave Ashima a feeling of solidarity. She was able to empathise with them. She realised that she was not the only person living with disability and there were others whose impairments were more severe than hers. She grew attached to the group and decided to work both for and with people with disabilities.

“The biggest thing is when I met with my disability group, then I saw that there are people whose hands don’t work, or many people can’t even get up from

bed so there was so much of problem. When I am with those people I feel that I don't have any problem, still I am cribbing so much about my problems. I have family support, financial support, I have good job and everything and I am independent and still I am crying. Then I felt that dear no, now no crying, in fact do something for others so that you feel life isn't that difficult."

Accepting Self: Route to a Positive Outlook towards Disability

Knowing about the situation of other people with disabilities helped Ashima learn to accept herself as she was. From this point onwards she began to appreciate her disability identity and took pride in celebrating the disability. She now believed that what mattered more than physicality was the attitude towards disability. So, having a positive mindset that embraces oneself the way one is, according to her was a way of negotiation while living with disability, for then the effects of disability will not matter much.

"When I met people with disabilities in a group then I felt that the more we crib about anything, the more problem will worsen. So, learn to accept, more than societal acceptance, one's own acceptance matters, that accept oneself. And in today's time I can face anybody, I don't have any problem in facing anyone. I don't have any problem with my disability. If you have won over your mind and heart, then body will remain like what it is. There will be no change but yes you will get comfortable living with problem."

At present Ashima is in a position of strength as she accepts a life with impairment in a sanguine way.

"I take disability as my strength as it has made me strong. This chair is not my wheelchair, it's my will chair means full of will power then I feel good. This helps me in moving so I take it positively."

DISCUSSION

The current paper depicts the experiences of a young woman living with a physical disability and shows how her sense of self evolved from being negative to celebrating the disability identity.

The study adopts the life story approach. As a research method this was deemed appropriate. While sharing their stories, people with disabilities bring up their needs, and these unheard voices, long suppressed, are an avenue for totally

different narrations of life experiences. It is believed that by listening to their voices the principles of inclusivity and empowerment can be imbibed, and can counter the societal notions that people with disabilities are inferior and voiceless beings.

The life story approach also gives the macro picture about how the teller's life is impacted by various events of life (Chataika, 2005). From Ashima's experiences of life with a disability, it is quite evident that disability is an outcome of both the impairment effects and the disabling barriers present in the environment. This finding is in congruence with what the International Classification Model of Functioning, Disability and Health (ICF) proposes, namely that an individual's health experience is the interaction between the health condition (biological dysfunction) and social, personal and environmental factors (Wade & Halligan, 2003). Ashima's medical journey was an ongoing affair from the onset of impairment until the day she realised she had no chance of being normal. This medical journey entailed both physical pain and psychological issues which, in combination with societal discrimination, added to Ashima's woes and thus exacerbated her experience of disability.

Research shows that disability is seen as a stigmatised identity (Goffman, 1963). For years people with disabilities have been living in a culture where charitable and medical views have invalidated their bodies. Such societal perceptions have led people with disabilities to regard themselves as inferior beings. Ashima's life story illustrates clearly that she was tormented by frequent questioning, labelling and the stares of people, on a daily basis. These encounters made her feel different, and eventually she began to define herself negatively because of the messages society was sending out towards her impairment. This is similar to the assertion of Guthrie (1999) that within a society that values perfectionist ideals of bodily beauty, gender and impairment converge to make the identity process more complex, and thus it becomes more difficult to maintain a positive identity as meeting the normative body standards appears to be a distant concept. This self-devaluation deepened further when Ashima did not see others who were living with a similar condition. She began to question, "why me?" The exclusionary practices of the society negatively impacted her sense of self. This is similar to what Morris (1991) stated with regard to the dominant ideology of subjection and how such messages of perfection and personal deficit are intensified. 'The messages we receive are very strong and clear and we have little access to different values which may place a more positive value on our bodies, ourselves and our

lives. Our self-image is thus dominated by the non-disabled world's reaction to us' (Morris, 1991).

The daily interactions rooted in discriminatory patterns took a toll on Ashima's well-being. In order to avoid these incidents she tried to conceal her disability by not using a stick or wheelchair, or remaining seated whenever people were around. The hiding of disability is one of the ways of managing spoiled identity, as mentioned by Goffman (1963) in his book, "Stigma: Notes on the management of spoiled identity". As Shakespeare (1996) said, coming out is not that easy, but definitely a difficult process full of obstacles. Ashima, while growing up, was devaluing herself based on societal perceptions, but her situation took a turn for the better when she came to know about other people with disabilities who were excelling in their domains despite their physical conditions. From these encounters she regained her sense of confidence. As she said, by being with other people with disabilities she realised that she was not the only one, which further boosted her sense of self. This exactly underpins what Morris (1991) called one of the salient features of the experience of prejudice faced by people, i.e., they suffer this as isolated beings. In other contexts where they interact, such as families, school, work or wider society, they encounter individuals without disability who fill their minds with their judgements, and people with disabilities live by and define their lives based on those perceptions. In contrast to this, when Ashima got acquainted with other people with disabilities she happened to encounter collective power (Shakespeare, 1996). This is in accord with the opinion of Weeks (1998) about shared identity, such that 'Identity is about belonging, about what you have in common with some other people and what differentiates you from others. At its most basic, it gives you a sense of personal location, the stable core to your individuality'.

By associating with other people with disabilities, Ashima interacted and participated in activities organised by disability groups. She felt connected with them and her sense of self was strengthened. She could now resist the labels or attitudes that society had targeted at her, and from this emerged her positive identification with the disability identity. Ashima's solidarity and alignment with other people with disabilities was a strategy to boost her self-esteem (Fernández et al, 2012; Darling, 2013; Dunn & Burcaw, 2013). This also confirms what Dunn and Burcaw (2013) mentioned, i.e., communal attachment, a recurring theme observed in the formation of disability identity. It involves not only having the feeling of connection with a disability group but also taking pride in disability

and finding this experience meaningful, as was observed in the life story of Ashima (Swain & French, 2000; Darling, 2013; Dunn & Burcaw, 2013; Nario-Redmond et al, 2013). This implies the significance of community, where people with disabilities actively engage with peers due to similar experience. There is research evidence that mentions community integration as “coming home” for people with disabilities (Dunn & Burcaw, 2013). In a similar vein, Johnstone (2004) highlighted the role of organisations for people with disabilities that aim at empowering and lending voice for people with disabilities. Barnes and Mercer (2001) mentioned this as common identity, where members of oppressed groups celebrate their virtues and thus support the concept of a disability culture which is an important factor in the formation of a disability identity.

Besides, having supportive and encouraging family members was the impetus for the positive affirmation of Ashima’s disability identity. Her family always stood by her and never hesitated to take her out or introduce her to others. This finding is in congruence with research that suggests that positive parental support and warm and loving behaviour act as contributing factors in managing life with disability and thus lead to enhanced self-concept (Wood, 1973; Bellin et al, 2007; Shah, 2010).

CONCLUSION

This paper underscores the importance of voice, agency and the celebration of disability identity thus challenging the stigmatised notions attached to disability. The paper reflects what Shakespeare(1996) said, that disability identity is all about having stories, giving the individuals a platform to share and recognising the differences, and all this starts by having a voice.

The story of Ashima is a testament of resilience and grit, as she emerges as a stronger individual who values her differences and takes pride in her disability identity. The research paves the way for future researchers to listen to the insider’s perspective in order to create a culture of valuing differences or, as Powel (1995) said, the emergence of a disability culture which is based on the insider’s perspective where people with disabilities share experiences that highlight their inner feelings, and not on how the condition is viewed by outsiders.

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Comprehensive Management of People with Cerebral Palsy: An Indian Perspective

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ABSTRACT

Purpose: *Guidelines for the management of people with cerebral palsy are available from many countries. However, these cannot be adopted in their entirety in other countries due to socio-cultural differences and varied health systems. This study set out to develop guidelines for the management of people with cerebral palsy, throughout their lifetime, in India.*

Methods: *A mixed methodology with a multiphasic approach was used. The first phase involved an extensive literature review to compile current evidence about the management of people with cerebral palsy. In the second phase, a questionnaire was given to stakeholders in order to explore current practices. The third phase consisted of consensus-building meetings with stakeholders, to develop resolutions that incorporate global best-practice recommendations for India.*

Results: *Responses from the second phase were compiled and categorised based on discipline. Proceedings of the consensus meetings were transcribed verbatim and best evidence was synthesised to understand current global practice guidelines. Resolutions were formed within the framework of the results of phases I and II. These were ratified by experts and then formalised.*

Conclusion: *Sixty-four resolutions were formed, detailing a framework for multidisciplinary management of persons with cerebral palsy throughout their lifetime. A card with guidelines was developed to document all aspects of rehabilitation, development and care. However, the utilisation and application of these guidelines have not been explored as yet.*

Key words: *SAKSHAMA, current practice of cerebral palsy care, lifelong care*

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INTRODUCTION

Cerebral palsy (CP) is defined as “a group of non-progressive, but often changing, motor impairment syndromes secondary to lesions or anomalies of the brain arising in the early stages of development” (Torjesen, 2017). CP is a common cause of childhood disability with an estimated global incidence of 3/1000 live births (Arneson et al, 2009).

While the needs of people with CP are unique and extensive, a significant majority have the potential to live independent and productive lives despite functional challenges. To achieve this, management must be ongoing and systematic. The obvious goals would be early identification of potential morbidities and focussed management to minimise such complications (Herskind et al, 2015).

The management of people with CP varies throughout India, with the emphasis limited to the early years of life. Although cerebral palsy has recently been included as a separate entity under the category of physical disabilities, despite the high prevalence the condition is not considered a public health issue in India. The management of children with CP is currently undertaken in hospitals and special schools; interdisciplinary management is rare. Moreover, healthcare disciplines in India, with the exception of rehabilitation disciplines (physiotherapy, occupational therapy, and speech and language pathology) have very little content on CP in their curricula.

Due to these challenges, it is imperative that uniform practice guidelines be drawn up in order to improve the quality of care, and ultimately the quality of life of people with CP. Guidelines for the management of CP exist in other countries but cannot be used in India without contextualisation and modification due to differences in healthcare delivery, and other social institutional systems. Guidelines in India are sketchy and limited to individual disciplines (Purohit, 2008). The recommended method of developing guidelines for medical disciplines with reference to best research evidence is by using the GRADE framework (Bhaumik, 2017). However, the GRADE checklist for forming guidelines does not include the value of social sciences research methodologies and this has been acknowledged as a limitation (Wang et al, 2018). Therefore, the current study did not use the GRADE guidelines but relied on: 1) a review of global guidelines, and 2) consensus-building meetings for feasibility and adaptation to the unique circumstances of the Indian health delivery services.

Objective

The study aimed to:

- 1) Conduct an extensive literature review in order to identify known risk factors, causal factors, prognostic indicators, robust outcome measures and management strategies for cerebral palsy;
- 2) Identify current practices in the management of people with cerebral palsy in India with reference to the first objective;
- 3) Develop an evidence-based guideline that is feasible, acceptable and applicable for the lifelong management of people with cerebral palsy in India.

METHOD

Study Design

This study used a multiphasic mixed-method design.

Participants

The study participants were persons with CP involved in advocacy, parents of children with CP, and professionals representing all disciplines involved with rehabilitation and care of a person with CP.

Procedure

Phase I: Literature Review - This phase consisted of an extensive literature review in order to synthesise scientific evidence on risk factors, causes and management of cerebral palsy in the various disciplines involved in the care of an individual with CP.

Literature was sourced from all available clinical practice guidelines, limited to the preceding 10 years. In the case of the social sciences only articles published from India were considered. The level of evidence of individual articles/ opinions was categorised using the guidelines of the National Health and Medical Research Council (NHMRC), Australia (NHMRC,2009).

Phase II: Survey to understand current practice - This phase was conducted through informal surveys to gather information on the current management

strategies used for people with CP by practitioners of various disciplines. A questionnaire, based on the evidence identified in phase I, was developed separately for each discipline and sent to 50 professionals in various disciplines all across India, using a snowball sampling technique. The questionnaire listed the recommendations for practice guidelines and the responses consisted of four options - “consistently followed”, “sometimes followed”, “never followed”, and “not aware”. Respondents were requested to provide information if their current practice differed from the guidelines listed in the questionnaire.

Phase III: Guideline formation - In this final stage, the results synthesised from the previous phases were used as a framework to guide a consensus-building meeting with experts and draw up guidelines (Tables 1-3). Experts belonging to healthcare disciplines, rehabilitation and social sciences disciplines, people with CP, and parents of children and adults with CP were invited to form ‘consensus’ groups in core areas: medical sciences, rehabilitation sciences and social sciences. Meetings were conducted separately for each group. All invitees had a minimum of five years’ experience in working with people with cerebral palsy and were considered experts in their field. All the sessions were video-recorded and then transcribed verbatim, including nonverbal communication where possible. The transcriptions were synthesised to form Resolutions with a level of recommendation and sent to the participants for clarification and confirmation. Following this process, the guidelines were circulated for ratification by professionals who were not part of the previous phases.

Table 1: Guiding Framework for Consensus Meeting with Medical Professionals

From a purely medical point how relevant are the NICE guidelines for us?

What are the major challenges?

Which classification is most useful for a paediatrician? For an Orthopaedic surgeon? For a Psychiatrist?

How feasible is it to refer to a rehab professional in the neonate period?

What are early markers that would help in flagging an infant?

Which is the earliest milestone that you consider for referral to rehab?

Any addition to standard risk factors?

What is a feasible and necessary follow-up schedule for an infant at high risk for NDD?

Which is the most feasible and sensitive scale for assessment? Cost, validity for India, norms for India.

What is the method to decrease loss to follow-up? Give a card like immunisation schedule?

Is recording of movement in NICU in India feasible?

Ethics?

What are the recommendations for MRI?

What are parent counselling recommendations? Who should do it?

Medication in high-risk pregnancies?

Pre-natal vaccines, vaccines for the child

NICU access to OT/PT

Referral to genetic testing? When?

Indicators?

What will be the changes to CP terms if genetic problems are identified?

When should the doctor elicit regression from the parent?

Counselling about having other children? Who should do it?

When is the earliest to refer to psychiatrist? Parent? Child?

Any difference in diagnosis of GI/ LD in CP different from TDC?

DIAGNOSIS- change from DD to CP

Systemic disorders when to screen? All time period.

Spasticity medication guidelines? Same as everywhere else?

Osteoporosis - when to test?

Correct age for Botox? Nerve block? Orthopaedic surgery?

Indications

Questions to identify atypical seizures

When to send to ophthalmologist?

Botox frequency for major muscles

Ortho Surgery for specific deformities- indications. Guidelines same as elsewhere?

Botox less than prescribed dose?

Hip surveillance - indicators

How often should be x-ray be done?

Vit D indications? Frequency?

Growth chart same as TDC?

ORAL HYGIENE and referral to dentist

Supplemental feeding recommendations

Questions to be asked for aspiration, constipation

Specific concerns for CP bowel - Irritable bowel?

Child with CP with mobility restrictions - diet modifications/ ADHD identification

When to assess for depression/ ADHS/ LD? Any specific differences from usual?

Behavioural problems - when to send to psychiatry? Tool to assess specific to India? Norms?

Disinhibition, stress- when should they be referred to psychiatry from psychology?

Table 2: Guiding Framework for Consensus Meeting with Rehabilitation Professionals

International Classification of Functioning (ICF)

Child Protection

Family-Centred Practice

Team Approach

Early Planning for Transition Periods

Clinical Measurement Practical Guidelines for Service Providers

Cultural Considerations

Definition

How is Cerebral Palsy Classified?

Goal Setting

Canadian Occupational Performance Measure (COPM)

Goal Attainment Scaling (GAS)

Classification Tools

Functional Motor Ability

Gross Motor Function Classification System (GMFCS)

Functional Mobility Scale (FMS)

Upper Limb Classifications

Manual Ability Classification System (MACS)

Communication Classification

Communication Function Classification System (CFCS)

Eating and Drinking Ability Classification System (EDACS)

Activity and Participation Assessment

Gross Motor and Mobility Assessment

Gross Motor Function Measure (GMFM)

3 Dimensional Gait Analysis (3DGA)

Observational (2D) Gait Analysis

Gillette Mobility Scale

Walk Tests

Timed Up and Go

Timed Up and Down Stairs

Fine Motor and Upper Limb Assessment

Quality of Upper Extremity Skills Test (QUEST)
 Assisting Hand Assessment (AHA) and Mini Assisting Hand Assessment (MINI-AHA)
 Melbourne Assessment 2: A Test of Unilateral Upper Limb Function (MA2)
 Shriners Hospital Upper Extremity Evaluation (SHUEE)
 Children's Hand-Use Experience Questionnaire (CHEQ)
 ABILHAND-Kids
 Box and Blocks Test
 Jebsen-Taylor Hand Function Test (JTHFT)
 Speech and Language Assessment
 Quality of Life Assessment

Table 3: Guiding Framework for Consensus Meeting with other professionals

Dental care

Referral for dental care, ear pain, facial pain, routine check-up

Dental hygiene is not a priority for parents

Dental curriculum to include

Type of dentist to refer

Early indicator of osteoporosis- OPG/ dental radiology Hyperactive gag reflex- type of toothpaste

Electric toothbrush after the age of

Nursing practitioners

PHC- screening and early identification of DD (TDS) AND EARLY IDENTIFICATION OF SECONDARY complications

Role of counsellor in hospital/ clinic OPD

Health education- personal hygiene, nutrition, skin, B&B, medication and side effects

Psychologists

IQ and ID are overestimation? Or accurate? Should parents consider that during school planning?

Early identification of learning precursors- when and who

Executive function evaluation and classification? Best way to assess

List of best tests for India and what they measure

Educational goal same as all children -RTE- Secondary school completion
Individual learning plan if not possible in mainstream, open schooling Therapy for cognition?

Aim for self-care/ participation?

RESULTS

The results of phase I are presented below in Table 4. The guidelines were extracted from the works of various authors (Ashwal, 2004; Adekoje et al, 2016; Anttila et al, 2008; Bax et al, 2006; Beckung et al, 2002; Blanchard, 2016; Byrne et al, 2017; Cerebral Palsy - Effective Health Care Program, 2011; Colvin, 2018; Hadders-Algra, 2014; Himmelmann et al, 2006; Morris et al, 2006; Morris, 2009; Novak et al, 2013; Padmakar et al, 2018; te Velde, 2019) for each group and these were considered as guiding documents during the consensus discussions.

Table 4: Sample List of Recommendations available from Existing Guidelines (results of phase1)

Factor	Age applicable
Established independent risk factors for cerebral palsy must be considered and children followed up consistently	Pre-natal and natal
Established causal factors for cerebral palsy must be documented and infants followed up consistently	Pre-natal and natal
General movement assessment must be used as a screening tool for all infants at risk for cerebral palsy	0-5 months
Multidisciplinary early intervention strategies must be begun in all children at risk/ screened positive for cerebral palsy	3-12 months

Parent education in the early months of the child's life is essential in children at risk / screened positive for cerebral palsy	3-12 months
Nutritional and energy evaluation must be done routinely especially for children with swallowing difficulties	1-12 years
Pulmonary evaluation must be done routinely especially for children with swallowing difficulties and those with total body involvement	0-6 years
Evaluation for gastrointestinal comorbidities must be done routinely	Lifelong
Cognitive behavioural issues must be identified	3-6 years
Evaluation for communication, speech and hearing, seizures, vision, oral hygiene must be conducted	0-3 years
Orthopaedic evaluation must be done for all children to screen for deformities/ pain	3 years - lifelong
Functional prognostic factors must be communicated to parents for future planning	18 months-3 years
Gross motor interventions, Assistive technology, Social support, Social interaction, Fine movement training, schooling and vocational assistance	12 months- lifelong

The results of phase II are given below in Table 5. The response rate was very low despite repeated attempts at eliciting responses. Moreover, responses were inconsistent even among professionals belonging to the same discipline.

Table 5: Distribution of Individuals who Responded (phase II)

Discipline	Number of Responders
Paediatrics	30
Physiotherapy	29
Occupational therapy	14
Speech language pathology	12
Special education	10
Orthopaedic surgeon	08
Medical social work	03
Clinical psychology	03
Nursing	03
Neurologist	01

Oral physician	01
Ophthalmology	01
Ear nose throat specialist	01
Psychiatry	01
Prosthetic & Orthotics	01

The results of the first two phases were discussed in phase III. The results of phase III are given below. Participant descriptions are depicted in Table 6.

Table 6: Distribution of Participants at the Consensus Meetings

Discipline	Number of Participants
Persons with CP	02
Parents of persons with CP	03
Paediatricians	03
Orthopaedists	02
Psychiatrist	01
Oral medicine specialist	01
Physiotherapists	09
Occupational therapists	04
Speech and language pathologists	04
Orthotic specialist	01
Clinical psychologists	02
Social workers	04
Special educators	04
Nurse	01

The Resolutions that were formed in the consensus meetings are presented according to the order of importance as deemed by the participants.

Resolution 1: Identification and registration - Classification of the child with CP was deemed essential by all participants, although different disciplines used various systems of classifications. Due to this inconsistency, it was opined that management was not consistent. One of the reasons was attributed to the lack of a national registry. It was resolved that until such time as a national registry is operational, a booklet similar to the immunisation card will be given to the parents of a child at risk for CP. This booklet will be considered as an identification/ registration card and will remain in the possession of the parents/ caregivers, and thereafter of the person with CP if the individual is competent to care for himself/herself. This booklet will give crucial timelines and information about the type of professionals to be consulted. It is expected that the booklet will

help to ensure that the relevant experts will evaluate the child/ person with CP at crucial intervals and thereby improve the care of the individual. Moreover, this booklet would form a record of the person's progress as well as the management provided.

The salient points of this booklet are given in the box below. The acronym SAKSHAMA (meaning "efficiency" in English) was considered appropriate.

SAKSHAMA bearing a unique registration number which can later be integrated into a registry:

Screening and surveillance includes early identification of neurodevelopmental delay, routine screening for secondary complications based on current evidence.

Assessment refers to assessment for formalisation of diagnosis and those undertaken by healthcare providers from time to time for various complications detected during screening.

Knowledge transfer refers to education about CP to parents and communication between professionals and inclusion of CP-specific content in curricula of healthcare providers.

Service provision refers to provision of healthcare and social services including assistive technology, social services and availability of required services.

Habilitation refers to optimisation of functional capabilities undertaken by rehabilitation professionals. This may happen in short spells throughout life.

Accommodation refers to the provision of and advocacy for reasonable accommodation at school, in public places and the workplace including accessibility, job modification and ergonomic solutions.

Management refers to strategies employed by all members of the team towards minimisation of disability and optimisation of function.

Assistance refers to the provision of human assistance in school, public places, work-places and care in the later years of life.

Resolution 2: The experts unanimously agreed that existing international guidelines are relevant and appropriate for India, provided the healthcare system is able to cope with it. The challenges that they faced were timely and correct screening of children. Therefore it was resolved that the guidelines in healthcare disciplines available from other countries, particularly from the National Institute

for Health and Care Excellence (NICE) (National Guideline Alliance, 2017) were relevant and applicable to India.

Resolution 3: The dental specialist and the psychiatrist opined that additional modules on CP should be integrated into their respective curricula. Alternatively, special course work should be made available, preferably through Massive Open Online Course (MOOC) platforms popular in India, such as SWAYAM, which is hosted by the Ministry of Human Resource Development.

Resolution 4: Government of India (GOI) to be petitioned to create a cadre of rehabilitation workers at the Primary Health Centre (PHC) level. These rehabilitation workers can undertake routine screening and ensure timely and appropriate referral. Moreover, they can also be trained to perform certain essential nursing and rehabilitation interventions. Trained professionals will supervise them on a consultancy basis, in line with the existing system of consultant rehabilitation professionals at the PHC level.

Resolution 5: The Trivandrum Developmental Scale can be used as a screening tool by Accredited Social Health Activists (ASHA)/ rural childcare workers (Anganawadi workers)/ PHC nurses to identify children with dysfunction during their first year of life, until a suitable alternative for a more valid tool like the General Movements Assessment (GMA) by Prechtl, (2005) can be developed.

Resolution 6: *The* GMA developed by Prechtl (2005) is the most valid tool available for early detection of neurodevelopmental dysfunction. Movements of babies at risk, who are in the neonatal intensive care unit (NICU) in secondary and tertiary level hospitals, must be video- recorded. A trained GMA practitioner must be available at these centres for screening and prescription of early intervention programmes.

Resolution 7: Magnetic Resonance Imaging (MRI) is indicated in children with clear risk factors and this must mandatorily be carried out two weeks after birth.

Resolution 8: As soon as a child is identified as “at risk for neurodevelopmental delay”, a psychiatrist with counselling skills must be involved in the team to prepare the parents for the future care of the child. The team must consist of the paediatrician, parents and other decision- making family members, a medical social worker and the psychiatrist. It is necessary to classify the parents’ receptiveness in order to plan for future counselling sessions/ flag in the SAKSHAMA booklet

Resolution 8 (alternative): If a psychiatrist is unavailable, the parents must be asked to fill out a translated version of the General Health Questionnaire (GHQ- 12), which must be assessed by a consultant psychiatrist and the need for counselling should be decided.

Resolution 9: Obstetrics and Gynaecology specialists must consider the use of steroids and magnesium sulphate supplements (MgSO₄) for high-risk pregnancies as per current evidence.

Resolution 10: Genetic screening should be done at age 9-12 months when syndromic features/any dysmorphisms are noticed. This is standard practice across the world to differentially diagnose CP.

Resolution 11: If a genetic disorder is diagnosed, the child must not be referred to as 'CP' in any health records thereafter. For purposes of social security only, the term 'CP' or any other suitable term may be used. This Resolution may be omitted once social security regulations are changed to include various other diagnoses. Currently all children with motor delay are termed 'CP' for purposes of disability certification in many states of India.

Resolution 12: The list of disabilities recognised by the GOI must be revised to include genetic conditions, in order to minimise the improper diagnosis of CP.

Resolution 13: CP should not be diagnosed as intellectual disability (ID) ,as is common now, unless the child does have intellectual disability as a comorbidity. This labelling forms a barrier for mainstream schooling.

Resolution 14: All children with CP who are unable to maintain sitting position and do not have independent mobility must be evaluated by a paediatrician / gastroenterologist for aspiration, gastroesophageal reflux disorder (GERD), and bowel dysfunction. This must be accomplished by the time the child is 12 months old. Nutritional assessment and need for alternate methods of feeding/ augmentation of nutrition must be considered.

Resolution 15: If a child is on parenteral/ gastric feeding, non-nutritive sucking must be encouraged and safety for conversion to oral feeding must be reassessed every three months. Gastrotomy site care must be taught to parents to avoid infection. PHC nurses must be taught to monitor and intervene when necessary.

Resolution 16: All children with CP, who are severely affected, must be assessed for malnutrition at three-month intervals. Anthropometry can be used as a screening

tool until 12 months of age but must be complemented with biochemistry analysis. After 12 months of age, anthropometry is unreliable as the child with CP who has severe mobility deficits is not expected to grow at typical rates. Hence other methods of screening must be utilised. As of now, anthropometric guidelines for children with CP do not exist for India. Guidelines from South Africa may be considered as a reference (Morris et al, 2006).

Resolution 17: Spasticity management using serial casting must be done only when the person undertaking this intervention is competent to cast and the child is monitored for 24 hours to ensure that there is no injury caused by casting. Children who appear to be malnourished must be handled gently to avoid risk of fracture. If the muscles do not yield with moderate pressure, casting must not be attempted and Botox is the safe solution.

Resolution 18: Indication for Botox must be assessed by two independent practitioners and the optimum dosage must be injected. Less than optimum dosage (currently done as an economical measure) must never be injected.

Resolution 19: In children with CP who are non-weight bearing, bone health must be assessed biannually. Radiographs and laboratory tests must be used to complement this evaluation. Vitamin D3 drops may have to be continued until three years of age for children with CP. Currently this is not a practice. Paediatricians must monitor at three-month intervals to avoid toxicity.

Resolution 20: Hip surveillance programme must be started biannually after four years of age for all non-ambulatory children. Physiotherapists must screen for clinical indicators and send for orthopaedic consultation if screening indicates a dislocation (decreased hip abduction range, limb length shortening). Hip radiograph must be taken in true antero-posterior (AP) view as per standard radiographic guidelines.

Resolution 21: Orthopaedic soft tissue surgical procedures must be performed only after seven years of age. Bony surgeries for alignment must be considered as elective and attempted only after the age of seven. An exception to this is in cases of painful hip dislocations which must be attempted as an emergency procedure.

Resolution 22: Mothers must be questioned on whether the child has seizures. These episodes can be upward rolling of eyes briefly, with crying normally immediately after waking up or prior to going to sleep. Other signs are upward rolling of eyes and sudden unresponsiveness and stiffening not related to normal

spasticity. Primary Health Centre nurses must be trained to identify and refer appropriately regarding this morbidity.

Resolution 23: All high risk babies must be screened for retinopathy of prematurity (ROP) at birth by a neuro ophthalmologist. Children with CP must undergo ophthalmological consultation for refractory errors such as strabismus at two years of age. Any error must be corrected immediately.

Resolution 24: Dental check-up must be done at the age of two years for developmental screening. Thereafter, annual check-up with the goal of preventive dentistry and management of oral hygiene and dental issues must be undertaken. One specific area of safety concern is posterior drooling which may cause aspiration. This must be evaluated and appropriate management commenced immediately.

Resolution 25: Children must be screened for attention deficit hyperactivity disorder (ADHD)/learning disability (LD) at age 4- 6 by a psychologist. Screening for depression must be done annually, especially during the transition years of 11- 18. If a teacher flags a child as a poor academic performer for intelligence, screening for LD must be done. Children with CP who have ADHD will not present in typical fashion due to mobility difficulties. Teachers and parents must be made aware of atypical presentations. If behavioural therapy is unsuccessful or inadequate, the child must be referred to a psychiatrist.

Resolution 26: The International Classification of Functioning (ICF) and the CP core sets form a relevant and easy to use framework for rehabilitation professionals but it was opined that the interpretation of ICF varies and hence training should be carried out among rehabilitation professionals. Such training can be offered in the form of a MOOC course. ICF core sets for cerebral palsy must be used as the guiding framework for assessment and goal setting.

Resolution 27: Local governments at district levels must be petitioned to stop the practice of giving out irrelevant and inappropriate assistive aids. These are cost intensive in terms of money and human effort, and counterproductive and often harmful to children with CP by increasing deformities and disability. Appropriate assistive technology providers must be solicited to provide appropriate aids and appliances.

Resolution 28: School-based therapies must be made available through the Sarva Shiksha Abhiyan, in addition to sensitising teachers on the abilities of children

with CP rather than focussing on their disabilities. Special training in current guidelines for management must be made mandatory through MOOC platforms for rehabilitation professionals working in the school system.

Resolution 29: Team goals, individually tailored to the child, must be formulated, keeping the child's social development in mind. Therapists must undertake holistic responsibilities to fulfil team goals and the use of ICF will aid this.

Resolution 30: Rehabilitation therapists must be vigilant to identify any signs of abuse and neglect and infringement on the child's human rights. This includes parents who insist on long hours of therapy at the expense of normal life roles, leisure, school and play. Identification of such parents and those who seem too tired must be done, for referral to a psychologist or social worker for counselling and assistance. Protection of the child includes counselling of parents and appropriate referral to social services/ advocacy groups for mainstreaming in education and employment for those with ability, and for supportive care for those with severe disability. Therapists must also be self-vigilant to avoid unnecessary and painful therapeutic procedures that may stimulate fear and crying in children. This must be avoided at all costs.

Screening of a school going child by a psychologist to identify bullying and / or neglect by teachers/ healthcare professionals/ family members and peers is also an important part of protection.

Resolution 31: Therapists must be aware of when and whom to refer to when they identify issues beyond their professional competence. These include potential seizures like stiffening, crying with eyes rolling back, lack of attention or seeming to "fade" during an otherwise engaging activity. When such behaviours are reported by parents or observed during therapy, children must be referred to a neurologist.

A child with failure to thrive or who seems to be tired and without enough energy must be referred for nutritional assessment.

A child who cries when a part (specifically the hip) is moved must be referred to orthopaedics to screen for potential fracture/ dislocation of the hip. A child with spasticity coming in the way of functional goals must be referred to a paediatrician/ neurologist/ orthopaedist as the case may be.

Children with dynamic spasticity and postural deviations must be referred to an assistive technology specialist for appropriate seating/ orthotic/ mobility devices.

Resolution 32: Physiotherapy must be undertaken regularly for the first three years of life and then the frequency must be reduced and the child must be seen intermittently when new goals surface or there is a new phase in the child's life. Therapeutic goals must be reviewed if a short-term goal is not met in 12 sessions.

After the first 8 sessions, parents must be efficacious enough to continue with routine management, and therapy time must be utilised for goal-oriented, active and skilful interventions so that there is optimum usage of time and financial resources. Goals must be focused towards functional independence to the extent that is possible based on functional classification systems (as relevant for the particular child).

Resolution 33: Parent education, conducted through focussed sessions, must form the most essential aspect of therapeutic intervention as one of the main goals of therapy is to increase the self-efficacy of parents and people with cerebral palsy. Parents and the adult with cerebral palsy must be educated to identify deficits/dysfunctions that require short-term therapy and seek appropriate therapy for intermittent short spells, including before and after orthopaedic intervention. Therapists must facilitate these short spells and not prolong therapy sessions with unreasonable goals and must counsel parents to have expectations reasonable with diagnosis, classification and comorbidities.

Resolution 34: Persons with CP must be followed up by relevant therapists weekly for the first three years, fortnightly until 6 years of age, every three months from 6-18 years of age, and annually thereafter in order to facilitate early identification of dysfunctions and optimum management. The exception would be if there is an acute dysfunction or elective surgery or other reasons that require intensive short spells of therapy to regain decreased function or optimise new gains.

Resolution 35: Following the fitting of any orthotic device or seating/ adapted device, the therapist must watch carefully for any pressure points or discomfort, and educate parents on don-doff schedules and how to keep a log of the child's behaviour in order to identify any discomfort and take remedial action immediately.

Resolution 36: Therapy goals must be individual-centred and must reflect the changing requirements and characteristics of the person, especially during transition periods. Goals must be broken down into short-term or micro goals, and must be specific, measurable, achievable, relevant and time bound (SMART). The Goal Achievement Scale (GAS) must be used to monitor progress.

The long-term goal must be articulated as a team goal and each professional must take up a part of it for their individual goal, e.g., the mothers may state that their goal is that the child must be able to join the family at mealtimes rather than be fed individually. Physiotherapy (PT) goal would be independent ambulation for 15 metres (to get ready and walk to the dining table). Occupational therapy (OT) goal would be independent sitting on chair and adequate fine motor function to perform eating. Speech and Language Pathology (SLP) goal would be appropriate or motor coordination for effective chewing, breath control and swallowing, while Psychology goal would be appropriate table behaviour. This will bring about integrated management.

Resolution 37: Therapists must use the SAKSHAMA booklet optimally to avoid using irrelevant therapeutic methods and draining emotional, temporal and financial resources. They must build on previous goals and interventions and must document these appropriately.

Resolution 38: The SAKSHAMA booklet must be issued only once. It must be issued by the first professional who identifies the need and challenges that require intervention. This may be the hospital where the birth takes place/ PHC or, in neglected cases, may be therapists. Prior to issuing the SAKSHAMA booklet, parents must be asked if they already possess one. All professionals must insist on seeing the booklet at every fresh visit.

Resolution 39: Linking the SAKSHAMA booklet with Aadhar (India's citizen card) is recommended as it is a lifelong requirement. However, confidentiality issues must be considered.

Resolution 40: Children with CP must be enrolled in the Anganawadi (community level pre- school system) as it is an important socialising environment. Prior to 3 years of age, a child must be trained to indicate wants and needs either through speech/ augmented/ alternative methods. The child must be trained to sit upright/ slightly reclined based on need for a period of time. Therefore, appropriate seating/ mobility device and communication methods must be taught to Anganawadi teachers and these must be provided to the children through insurance schemes. Currently, seating devices that have been appropriately designed for individual children are not provided.

Resolution 41: Assistive technology assessment must be undertaken with a multidisciplinary team consisting of physician, physiotherapist (PT), occupational therapist (OT), orthotic specialist, speech language pathologist (SLP) and medical

social worker (MSW). These assessments must be undertaken at 3 years, 6 years and thereafter annually until the age of 18, and then as needed. This provision must be made available at the district level and a camp method can be used if it is difficult to have consultant professionals. This is currently followed across large parts of the country.

Resolution 42: Occupational, employment and recreational needs must be assessed with a culture appropriate tool at the PHC level or school. A specific tool was not recommended.

Resolution 43: Each healthcare discipline must use sensitive and valid methods of assessment. These must include tools that measure body structure, function, activities and participation and contextual factors. Some of these include but are not limited to gross motor functional measure (GMFM), muscle strength measurement in functional methods, range of motion (ROM), activities of daily living (speech, swallowing, drooling, selective motor control, or motor function), behavioural measures, Edinburgh visual gait scale, energy expenditure index for GMFCS I-III, Melbourne hand assessment, breath holding time, cardio vascular endurance measures for older people, and language assessment using relevant language versions of Language Proficiency Profile (LPP) which is a standard language assessment tool used in India.

Resolution 44: Adolescents and adults with CP must be encouraged to engage in fitness programmes in adapted environments. This is an important preventive measure for lifestyle diseases. Gyms and swimming pools must be made wheelchair accessible and safe. Adolescents and adults must be assessed for pragmatic components of speech prior to enrolling in college/ joining work, and appropriate therapy initiated.

Resolution 45: People with CP living independently must be assisted by helping with access, ergonomics and reasonable accommodation by PT/OT/MSW. Employers must be given information and reasonable accommodation must be legislated.

Resolution 46: PHC workers and school teachers must be educated on selection of appropriate assistive aids. Companies engaging in corporate social responsibility activities for people with disability must be educated about giving appropriate and usable mobility and walking aids. Currently a “one size fits all” mechanism is used which is counterproductive.

Resolution 47: Mainstream schools must have provision for visiting therapists so that children can get therapy in school. This can be an extension of the current Sarva Shiksha Abhiyan programme which is a school inclusivity programme. The professionals must be appointed based on the number of children and must include all disciplines. The professionals will evaluate and make a plan of care to be followed by parents/ teachers/ assistants, and they will visit regularly for follow-up and revision. This is over and above the aforementioned Resolutions. Healthcare must also be addressed, including urinary tract infections, skin infections, etc., preferably by a nurse practitioner on the team.

Resolution 48: Community-level workers must be selected and appointed, and professionals must be involved in training them to screen, identify new onset dysfunctions, access government schemes and refer appropriately. They must have refresher courses annually on the lines of SSA teachers. In case of positive screening results or doubt, they must be trained to refer to the appropriate professional at the relevant healthcare level. They must be trained to create awareness and dispel the taboo of using a wheelchair/ walking aids.

Resolution 49: PHCs must have assistive aids like client hoists and special wheelchairs available for rent. Moreover, appropriate wheelchair transportable two-wheelers and four-wheelers must be manufactured at affordable costs. A list of resources must be made available to PHCs periodically.

Resolution 50: Parents of people with CP need respite. Therefore it was resolved that the PHC/ Anganawadi must have a day-care centre with a qualified nurse to supervise, and a ratio of 1:8 community worker to children with CP (also taking into consideration male/ female profile). This will have the added benefit of allowing the children to be routinely screened for health, hygiene and rehabilitation needs by the nurse.

To achieve this, nurses must be provided additional education in feeding, swallowing, gross motor and fine motor aspects. This service must be augmented by consultant therapists, dentists and physicians.

Resolution 51: At least two medical social workers must be appointed at each block level so that they will be able to counsel persons with CP and caregivers on social security schemes, healthcare access and schooling, employment and improving access.

Resolution 52: The curricula of special educators, nursing, dentistry, and medical social work must be augmented by a module on CP as this is a common cause of impairment.

Resolution 53: Accessibility must be achieved through participatory means. Local solutions to mobility aids and other devices must be developed at the community level to assist parents to take care of severely impaired individuals with cerebral palsy as they get older.

Resolution 54: Assisted living centres must be made available, keeping human rights, dignity, health and hygiene in mind, at Taluka/ district level based on necessity.

Resolution 55: Centres in India which have adopted best practices (e.g., Madhuram Narayanan Centre for exceptional children, in Chennai, has “Upanayanam” cards; Vidyasagar, in Chennai, has a module called “Let’s play”) can be emulated across the country with relevant translations.

Resolution 56: The PHC staff or community workers must ensure that all children at risk for CP are given the SAKSHAMA booklet immediately upon birth/ upon diagnosis.

Resolution 57: The community workers and PHC staff will mandate that every child with CP attend the day care or Anganawadi until the age of 6 years. After the age of 6 years the children must be enrolled in school or, for those with severe disability, they must continue to attend day care so that optimum screening takes place.

Resolution 58: The PHC nurse must do a routine nutrition, health and hygiene assessment every month and administer appropriate education to the caregiver.

Resolution 59: The PHC nurse or a nurse practitioner from the district level will conduct regular classes for parents on care, referrals, nutrition, immunisation, gastrointestinal problems and counsel them on therapy with the concerned specialists on mobility, self-care, hand function, eating, swallowing, oral health, communication and behaviour. They will play a crucial role in ensuring enrolment in the Anganawadi and school, and in having realistic expectations. They will also create awareness to dispel superstitious beliefs which can potentially be harmful to the child’s safety and security.

Resolution 60: Government schemes for CP must have dental professionals, nurse practitioners and special educators in addition to the existing professionals.

Resolution 61: A medical social worker with training in disability legislation must visit the necessary PHC and address parents on government schemes and provisions. Moreover he/she will facilitate access to these provisions.

Resolution 62: In the transitional ages, a clinical psychologist must assess the person and initiate counselling or therapy to minimise behavioural issues, anger and coping. Moreover he/ she along with the nurse practitioner and medical social worker will undertake counselling on sexual behaviour, substance abuse and refer appropriately as needed.

Resolution 63: The psychologist, occupational therapist, medical social worker and special educator will screen children at 12 years to decide on the future path – mainstream education/ vocational training/ custodial care/ assisted living options.

Resolution 64: The government must be petitioned to consider the rehabilitation needs and social needs of independently living persons with CP, and to bring out an insurance plan commensurate with their needs, from screening to custodial care and throughout their lifespan.

DISCUSSION

This project set out to develop feasible care guidelines for persons with CP. Although the condition is well recognised in India, no systematic method of assessment and management exists in the country for people with this disorder. One of the reasons that emerged from non- responders in phase II of the study was that professionals and parents had a pessimistic attitude towards CP as it cannot be cured. Moreover, there is an opinion that most people with CP have intellectual disability and hence not much progress can be achieved. These factors must be addressed through awareness programmes. This aspect was developed into a Resolution because it was considered to be beyond the scope of this project. The current project was limited to care of the person with CP, and governmental actions regarding policies were not within the ambit of the consensus group. Petitioning policy-makers will be taken up as a future direction. The evidence guiding medical care developed in other countries, particularly the UK, related to care of people with CP can be adopted in India without modification. Experts opined that the barriers to implementation of NICE (2017) guidelines in India

were the lack of training of professionals on care of persons with cerebral palsy, and economic and healthcare access.

In the case of dentistry, speech and language pathology, clinical/ rehabilitation psychology, medical social work and nursing, the curriculum does not deal adequately with cerebral palsy. Hence it is highly recommended that additional modules on CP should be incorporated into the curriculum. Until this is effected it is recommended that online tutorials through MOOC platforms be created to upskill professionals in these disciplines.

In the case of physiotherapy, occupational therapy, prosthetics and orthotics, there are multiple challenges. These challenges include inadequate exposure to evidence-based curricula, costly and culturally inappropriate measurement tools and outcome measures, and cost of training for CP specific management strategies.

The core members of the interdisciplinary team involved in care of persons with cerebral palsy must include dentists, psychiatrists, gastroenterologists, ophthalmologists, nurse practitioners and assistive technology specialists, in addition to the commonly accepted team members. These additional members would act as consultants and their services will be obtained through the SAKSHMA booklet.

The greatest challenge to providing adequate care to persons with cerebral palsy is the poor acceptance of the prognosis by parents, and their unreasonable expectations from therapies provided. Often, parents continue therapy for years hoping for normalcy, instead of enrolling the child as early as possible in regular or special schools. Awareness programmes, sponsored by the government and using mass media, as well as mandatory training for all healthcare professionals in counselling, may alleviate this challenge over time. This was beyond the scope of the current project and is a future goal.

The SAKSHAMA booklet with a unique number, along the lines of the immunisation card, is a feasible way to maximise professional assessment and management in a timely manner for people with cerebral palsy. This can be a precursor to a web-based registry.

Training of community-level workers and provision of an interdisciplinary professional consultancy team at each PHC level is an urgent need.

Provision of aids and appliances that are unsuitable and potentially unsafe is uneconomical and a waste of manpower, and must be replaced by individualised assessment and provision of appropriate assistive technology at regular intervals.

Limitations and Strengths

The major limitation of this study was the poor response for the phase II survey. Several attempts (maximum of 10) were made to contact the persons identified, but to no avail. One reason that is hypothesised is the overwhelming amount of work that clinicians normally handle, making it difficult for them to engage in research. A major strength was the success of the consensus-building meetings which allowed the researchers to develop methods that are feasible in India and will integrate into the existing healthcare system. The extensive literature review undertaken for best research evidence was another strong point. The consensus-building meetings were rich in content and the Resolutions were comprehensive. The active participation of all consensus group participants was an asset. The Resolutions developed in this project are the opinions of those who participated. It is possible that there might be differences of opinion from other practitioners. Efforts were made to get opinions from all over India, but due to poor response rates this was not achieved. This is acknowledged as a limitation of the study.

From the results of this study, it is evident that limitations in knowledge, poor awareness and inadequate social security remain the greatest challenges limiting participation of people with cerebral palsy and impacting their quality of life and their caregivers. These guidelines are an initial attempt to guide persons involved in the care of people with CP holistically.

CONCLUSION

Guidelines for early detection, early intervention and continuous evaluation and follow-up, as well as supportive care of persons with CP and their caregivers, have been formulated for India with the participation of multiple stakeholders. The 64 Resolutions provide a road map for community-level health practitioners on referral and provision of services within the existing healthcare system.

Implications for Rehabilitation

- The management of chronic conditions require a multidisciplinary approach and therefore the management guidelines should be developed by a broad group of stakeholders.

- Cerebral palsy is an important lifelong potentially disabling condition and requires a lifelong approach.
- Pure research evidence is inadequate for practical purposes as actual situations vary in different countries. Therefore, practice guidelines must include stakeholder preferences to make them acceptable and relevant to local situations.
- A management framework such as the guidelines which was developed with the input of all stakeholders is expected to be acceptable for all rehabilitation providers and is expected to result in more effective interventions.

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Appendix:

Sample Questionnaire used in phase II

Survey

Name (optional):

Speciality:

Type of Institution:

Average number of persons with cerebral palsy seen per month:

Do you follow the current guidelines (attached) of care for CP relevant to your discipline: Please note your answer against each recommendation using the following options:

Recommendation	Consistently followed	Sometimes followed	Never followed	Not aware
1				
2				
3				
4				
5				
6				
7				
8				
9				
10				

If not, please describe your routine care protocol:

What are the challenges that prevent you from adhering to guidelines?

Training in Qualitative Research Methods for Professionals working with Persons with Disabilities

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ABSTRACT

Purpose: *The study aimed to investigate the impact of intensive in-service training in qualitative research methods on the research competencies of a cohort of rehabilitation professionals.*

Method: *A series of three-day workshops was held on professional development in the promotion and utilisation of qualitative research in the field of disability and rehabilitation. It was organised at five centres across India for professionals working in that field. Data was collected through a survey of workshop participants, to ascertain the impact and efficacy of the training provided.*

Results: *The results suggest that practitioners working in the area of disability and rehabilitation see considerable value in the application of qualitative research and are enthusiastic about its potential to improve the lives of those with whom they work. They believe that such an approach will provide useful data and increased knowledge in respect of the lives of individuals with disabilities and those interventions that provide them with greatest benefits. The survey revealed that the knowledge of qualitative research methods was limited even among professionals who had studied for research degrees.*

Conclusion: *There is the need for more intensive training in qualitative methods in order to enhance the quality of research in disability and rehabilitation in India, and to assist in improving the lives of individuals with disabilities, their families, carers and those who work with them.*

Key words: *professional development, training rehabilitation professionals, in-service training, short-term training, disability rehabilitation training India*

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INTRODUCTION

In India, as in many other countries, research into disability and the provision made for people with disabilities has been conducted within a long-established positivistic tradition (Grills et al, 2017; Massenburg, et al, 2017). This was evident in the survey of published research into intellectual disability conducted by Reddy and Narayan in 2007, which showed that even small-scale studies tended to report on data collected using quantitative methods (Mukhopadhyay and Gupta, 2014; Sarma, 2015). Within the positivist paradigm there has been a demand for statistical data which can be used to identify trends and patterns based upon large samples, allowing for generalisation to a wider population. This scientific approach based on the traditions of positivism has proven useful in respect of providing a broad overview of issues on a national or regional scale (Visser, et al, 2016). The approach has been important in enabling policymakers, or those charged with the management of resources, to make plans for provision to improve the lives of those living with disability. The collation of statistical data based upon large-scale surveys, has been widely accepted as an appropriate means of understanding complex situations that impact policy and provision in the field of disability studies (Anderson, Larson, Lentz and Hall-Lande, 2019). However, the results of such studies have been found to have limited use in respect of influencing the day-to-day practices of professionals working most closely in the provision of support for individuals with disabilities or their families (Shakespeare, 1996; Kröger, 2009).

Critics of traditional research in this field (Moore , Beazley and Maelzer, 1998; Fawcett, 2014) have focused on several shortcomings. First, quantitative investigations have tended to research “on” or “about” individuals, not “with” them, and have therefore ignored the voices of those most directly involved in provision and practice (O’Brien, 2020). Secondly, much of the reporting of quantitative research has made use of procedures and language that is opaque to the majority of service-users and providers (Schwartz, Kramer, Cohn & McDonald, 2020). Thirdly, those who have been engaged in the research have operated at a distance from professionals responsible for delivery of services and have failed to adequately contextualise real-life situations when presenting their findings (Shaw & Lunt, 2018).

The authors of this paper find themselves in sympathy with the opinion that whilst positivistic studies may still contribute to our understanding of disability, interpretivist approaches based upon the collation and analysis of qualitative

data have greater currency for the improvement of practice. It is with this view in mind that they have made a commitment to work with other colleagues to promote qualitative research methods within an Indian context.

Why Qualitative Research?

In some disciplines there have been debates about whether qualitative research can achieve the rigour that has become associated with traditional positivistic approaches (Chavan, 2015). Sarma (2015) makes a good case for the use of qualitative methods, suggesting that such an approach has made a significant contribution to the development of knowledge and understanding in disciplines including sociology and political science, in India as elsewhere. However, he acknowledges that some of the criticisms levelled at researchers working within an interpretivist paradigm are justified, because of poor practices that have not ensured the trustworthiness of some of the results produced through the use of qualitative research tools. Ensuring research rigour is an essential factor in gaining the confidence of those professionals who have come to believe that investigation is dependent upon the presentation of statistically verified data.

Binder et al, (2016) propose that qualitative methods in researching clinical practice should be recognised as an effective means of investigating the experiences of both clients and therapists. Such methods, they believe, can provide critical insights into the relational context of clinical interventions and their impact upon the recipients of these interventions. These researchers suggest that many professionals working in the caring professions are familiar with the presentation of cases. However, these case histories are often based upon limited epistemological and methodological presentation that would enable the greater validity that researchers demand when presenting data (Bergmark, Bejerholm & Markström, 2018).

On occasion, a qualitative approach may form part of a mixed-methods investigation, to enable a deeper meaning to be applied to the interpretation of statistical data gained through use of quantitative instruments (Corby & Sweeney, 2017; Higashida, 2017). But in many circumstances qualitative approaches can be the primary or even the sole means of data collection and analysis, particularly when the researcher needs to understand environmental factors or the effect of interventions that impact the lives of those who are the focus of the research (Forrester & Sullivan, 2018; Prasad, 2018).

Morrow (2007) suggests that qualitative research provides a useful means of gaining understanding of the meanings that individuals make of their experiences. Through the use of qualitative methods such as interviews, the researcher is able to probe deeply into the experiences of those within a purposive sample in order to make sense of their lives and to gain rich data. Cornelissen (2017) endorses this view and believes that qualitative methods may provide the only effective means of understanding how organisations work and their impact upon both individuals and the effectiveness of intended institutional outcomes. Cornelissen identifies distinctive aspects of qualitative research that he believes to be the strength of this approach. Specifically, he discusses the ability to develop “thick description” through which, with the use of methods that may include in-depth interviews or focus groups, the researcher is able to explain the details of an organisation and its structures in a manner that enables the user of the data to understand relationships and the impact of the actions taken within this organisation. For example, a researcher who wishes to understand the effectiveness of a clinic in delivering physiotherapy services to a group of clients with physical disabilities, may interview service-users and providers to gain the lived experiences of those associated with the clinic.

The Need for Professional Development in Qualitative Research Methods

Opportunities to gain focused training in the use of qualitative research methods for investigating disability issues in India and other parts of Asia have been limited (Horta, 2018; Shin, Postiglione & Ho, 2018). Universities providing doctoral level qualifications in the social sciences and disability studies have tended to provide a narrowly focused provision of methodological training, largely related to quantitative approaches (Ali et Al, 2017). Innovation in research training has been slow to develop. Dash (2015) reported some of the challenges in developing programmes for capacity building in post-graduate research programmes in India and Malaysia, suggesting that there is a lack of clarity about the type of research that can best be deployed to raise the quality of investigation in these countries.

Bowden and Green (2019) describe how in many countries the nature of post-graduate research training has changed in order to address the various national, educational and economic policies being implemented. In particular they describe inconsistencies in the support provided to novice researchers which places some at a considerable disadvantage, in a climate where research expectations are

rapidly changing. Nchinda (2002) described evidence-based decision-making as a critical factor in promoting effective health interventions. An important factor raised in his study is that of ensuring that national context is given a priority. He uses the phrase “indigenous research capability building” to describe a process, where research training is provided in-country, using exemplification from investigations conducted locally in order to promote research methods that are appropriate and can be applied within national resources. This may be particularly important when attempting to promote changes or introduce new approaches in situations where research is relatively well-established but possibly dependent upon a narrowly focused set of principles.

Development in the field of disability rehabilitation, inclusive education and early intervention has been rapid in recent years. The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, 2006), the Agenda for the Sustainable Development Goals (SDG, 2015), particularly SDG 4 of SDG 2030, with its focus on inclusive education and other international mandates have emphasised the priority and focus on equal opportunity and equity among people in general and disadvantaged populations in particular. As a result, various programmes have been initiated universally for the development of provision and practice (Collins, 2012; Baldiris-Navarro, Zervas, Fabregat-Gesa & Sampson, 2016). To keep pace with these developments, professionals need constant updating to equip themselves with knowledge, skills and competencies to participate and contribute to the cause of realising the rights of a marginalised population. Staff development programmes clearly have a large part to play in such developments (Chiaburu & Marinova, 2005; Jellema, Visscher & Scheerens, 2006).

Many universities and professional organisations provide professional development at Bachelor and Master’s levels, with course content covering research methods. An examination of the research conducted in disability in the country, has predominantly focused on the collection of data using quantitative research methods, with qualitative approaches having gained currency relatively recently (Mehrotra, 2012; Kaur, 2016). Quantitative research plays an essential role as it provides an insight into the status of phenomenon at ‘length and breadth’, an approach that may provide guidance for policy decisions and areas requiring in-depth studies (Choy, 2014; Jamali, 2018). Quantitative research helps to quantify the findings by generating numerical data that is analysed using appropriate statistics, whereas qualitative research helps by creating an ‘in-depth’

understanding of the behaviours, attitudes, events, interactions among people and their environment, and other processes of daily life. Qualitative researchers stress the socially constructed nature of reality, the intimate relationship between the researcher and what is studied, and the situational constraints that shape inquiry (Norman & Lincoln, 2005; Nakkeeran & Zodpey, 2012).

In the area of disabilities, every person matters and his/her concerns in life need to be addressed as he/she has the right to a life with dignity. Such details can be understood only by qualitative research that looks at the 'depth' of a phenomenon. This research method requires training in order that the researchers carry out the task professionally to make the findings meaningful. Such studies are few in India. A search for qualitative research literature from within the country reveals a scarcity of such materials (Herur, 2016). In acknowledging this situation, the current study aimed to conduct in-service training for professionals working in the area of disability rehabilitation in different parts of India, and to analyse the impact of training on their conceptual understanding and appreciation of the applicability of qualitative research methods.

In order to gather data to investigate this issue, the following research question was defined:

What is the impact of intensive in-service training in qualitative research methods upon the research competencies of a cohort of rehabilitation professionals?

METHOD

Setting

The project was established as a collaborative effort of the National Institute for the Empowerment of Persons with Multiple Disabilities (NIEPMD), a research and training institute established by the Ministry of Social Justice and Empowerment, Government of India, and the University of Northampton, UK. The NIEPMD contacted organisations throughout India that conduct research and training programmes in the area of disability rehabilitation, inviting applications for a training programme on qualitative research methods to be conducted by the expert team from the University of Northampton. Considering the social, cultural and linguistic variations of the country, it was decided to conduct the training programmes in five zones of India to provide wide coverage.

Participants

The eligibility criteria for course participation focused on those having a PhD or currently registered for PhD and teaching courses in disability and rehabilitation at the Bachelor or Master's level. For each zone the applications were reviewed by a team at NIEPMD, and those participants who fulfilled the participation criteria were included in the programme. The participants were informed that the effect of the training programme on the participants' acquisition of knowledge on qualitative research methods would be studied and the details would be published. After this their informed consent was obtained.

There were totally 144 participants in the training programme. They consisted of 55 male and 89 female participants. Among them, 26 were from Chennai, 17 from Delhi, 30 from Kolkata, 38 from Hyderabad and 33 from Kozhikode. A majority of the participants were educators, teacher educators and special educators (88). Other professionals represented were psychologists (25), speech pathologists (9), research scholars (7), prosthetic and orthotic engineers (4), physiotherapists (3), social workers (3), occupational therapists (2), administrators (2), and a librarian (1).

Programme Content

The programme content comprised a series of taught sessions and practical activities that covered a broad range of critical qualitative research issues. These included question generation, ethical procedures, research design, ethnography, case study development, grounded theory, managing research literature, conducting interviews, focus groups and observations, coding and data analysis, writing a research proposal and reporting procedures.

Tools

The team, which comprised researchers from the University of Northampton based in both UK and India, prepared a pre- and post-test questionnaire with 30 close-ended questions addressed through a multiple-choice format (Bennett, 2003; Oosterveld, Vorst & Smits, 2019). The content of the pre-test questionnaire included concepts of what was to be covered during the training programme. The close-ended questions were the same in the pre-test and post-test questionnaires. While the open-ended ones in pre-test were framed to elicit information on the participants' expectations from the training programme, the post-test had questions on the understanding of course content and how their learning might be

applied, and about the actions that might be taken to improve such programmes in future.

Procedure

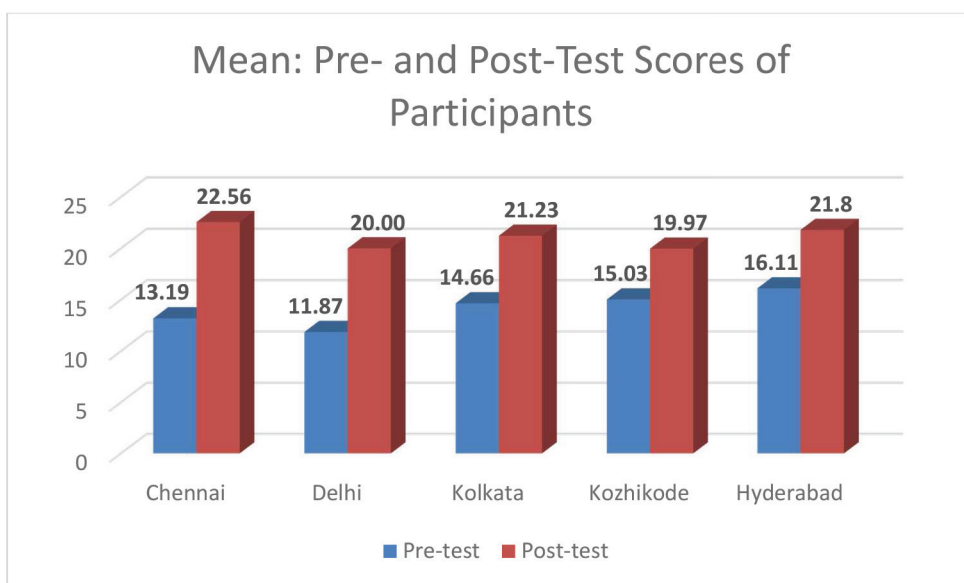
As described, the training programme was organised in five different locations in the country to facilitate participation from most parts of India. The duration of the training programme was three days. Following the pre-test on the first day, an introduction to the course was presented by the team leader and the programme was conducted with hands-on exercises and peer interaction to ensure that each concept taught was followed by an exercise of application. In all five zones, the pattern of the training and the training material shared was identical, to ensure uniformity. The programme provided considerable opportunities for the participants to discuss and share ideas and concerns with resource persons and among themselves. At the end of the training, the post-test was conducted. In addition, the interested participants were invited to conduct an exercise on developing a research proposal on given guidelines and to submit it a short time after course completion. They were informed that those participants who completed this task were found to meet the selection criteria and, following analysis of test data, would be invited to participate in the second level advanced training to be conducted by the University of Northampton resource team members at a later date.

RESULTS

On analysing the results of pre- and post-tests, it was noted that in the close-ended questions, there was a significant gain in the post-test scores when compared to the pre-test scores on a maximum score of 30. (Pre-test mean score = 14.172; post-test mean score = 21.112; mean gain = 6.94). On conducting t-test, the t value was found to be 2.13 with the significance at $p < 0.001$. Table 1 shows the zone-wise mean scores of pre- and post-tests, clearly indicating that the post-test performance was superior to the pre-test. The result is an indication that for professionals with research qualifications or prospective research scholars in the field of disabilities, participating in a well-planned three-day training programme on qualitative research tends to equip them with knowledge on the subject. The finding concurs with the study conducted by Narayan and Reddy (2008) who carried out a three-day in-service training programme for middle-level functionaries in community-based rehabilitation where they found that a three-

day programme involving hands-on experience was effective and that a follow-up after three months revealed that the learnt skills were retained. Furthermore, Chaghari, Saffari, Ebadi & Ameryoun (2017) who undertook a qualitative study in Tehran, involving an in-service training programme for 25 nurses on in-patient care using the model of empowering education, found that this approach facilitates occupational tasks and improves the competency and professional skills among nurses. They added that in this regard, poor organisational settings might hinder the successful implementation of an empowering education model, which can be promoted through participation of the senior managers.

Table 1: Mean Scores of Pre- and Post-tests



Qualitative Data Analysis

For analysing open-ended questions through which qualitative data was collected, Creswell's (2008) visual mode of the coding process was adopted. Through this process it is possible to analyse text and to elicit key themes that recur in relation to the research questions (Eliot, 2018). This process was also taught to the trainees as part of qualitative data analysis procedures. Most of the themes were predetermined or 'theory driven' while others emerged from the data or were 'data driven' (Braun and Clarke, 2006). In the pre-test, the participants were asked to respond regarding three important issues/themes: (1) their expectations about

the course, (2) utility, i.e., what they hope to achieve through this training, and (3) further information, if any, that they would like to engage with. In the post-test, they were asked to respond about: (1) what they had learned (Knowledge level), (2) how they would have applied the knowledge from the training (Application level), and (3) additional information including benefits of conducting qualitative research.

With these six predetermined broader themes in mind, responses from the trainees were transcribed, collated coded and amalgamated under each theme. In response to Creswell's (2008) visual mode of the coding process, five stages of the data analysis procedures were followed. Applying this approach, an initial read through of data and repeated reading by multiple analysts was completed in the first stage. The purpose was to become familiar with the data and identify the locations within the wider texts where meanings and patterns could be highlighted. In the second stage, familiarised data was made into segments with the purpose of generating initial codes. Larger texts were segmented, according to the predetermined themes a process that identified many segments of texts where initial codes emerged. Thirdly, coding of segments was undertaken. The intention for this particular study was to develop multiple codes with reference to initially developed broader themes. At this stage, relevant coded extracts within the themes were collated and organised accordingly. Though one researcher was entrusted with the development of codes in the earlier stages, paired coding and later, joint coding were adopted from this stage onwards. This was to strengthen the inter-rater validity and ensure the contributions of all researchers achieved analyst triangulation. There were many codes identified; for example, level of confidence (coded as LC=level of confidence) in applying knowledge earned through the training, and specific learning examples (SLE) that exemplify trainees' learned outcomes. Other codes emerged such as the 'critique of previous knowledge' (CPK) and 'addition of new knowledge' (ANK). Similar overlapping or redundant codes were combined to form reduced number of codes; for example, 'a comparison of previous and new learning' (CPN) in the fourth stage, after a review or refinement of the codes developed in the third stage. A particular code was also developed to exemplify specific learning outcomes that are particularly 'relevant to the field of rehabilitation and disability' (RRD). In the final stage, different codes were collapsed together according to their common characteristics, to develop final thematic codes or themes. This provided a satisfactory thematic map of the data gathered for the study.

Similar procedures have been advocated by Braun and Clarke (2006) who provide examples of how to address the issue of redundant codes. Following their model, some changes were made in the predetermined codes of themes; for example, one of the pre-test themes, 'further information' deemed to be indistinguishable from the post-test theme of 'additional information'.

The final themes identified provided the focus of discussion and were defined as Expectation of the course (E), Usefulness of the course (U), New knowledge (N), and, Application of new knowledge (A). An additional theme described earlier was the benefits of doing qualitative research (B).

Analysis of the qualitative data revealed the following:

All the participants believed that they had gained from the training and increased their level of knowledge and confidence in respect of qualitative research methods. Furthermore, they suggested that they would be more confident in developing and applying qualitative research after attendance at this course. For example, one participant stated that she had got:

"Better clarity about qualitative research, and how to generate research questions in qualitative research, the philosophy behind the qualitative research, its interpretivist world of knowledge construction, theoretical framework, grounded theory and ethnographic research."

When asked about specific learning gained through the research training, typical replies included:

"I have learnt basic terminologies of qualitative research."

"Learnt to conduct qualitative research, focus groups, interviews, case studies, and observations."

"Research process of qualitative research design," and "how to address ethical issues in participatory research."

With regard to the benefits of doing a qualitative research course, participants often focused upon the greater depth of understanding about individuals or groups that could be gained from qualitative data. As one commented:

"It is possible [through use of qualitative approaches] to process an in-depth understanding of the complex nature of individuals with disability and other diverse needs and to improve the quality of life of those individuals."

Some participants (N=10) also expressed the value that they had gained through a greater understanding of the relationship between qualitative and quantitative research methods and the possibilities of utilising a mixed-methods approach. When asked about their understanding of the differences between qualitative and quantitative methods and their applicability in the field of disability and rehabilitation, they were able to articulate ideas which generally favoured qualitative approaches for the more democratic and client-focused opportunities that came with these. Course participants who came from a medical or para-medical background had experienced the use of quantitative research data but believed that the more personalised data that could be obtained from qualitative approaches were likely to have a greater impact upon practice.

A significant learning outcome from the course was the level of confidence expressed by participants in their ability to apply newly gained knowledge to develop a research proposal. Some considered that small purposive sample research held value for practitioner researchers who wished to understand specific client needs or the value of interventions or changes to practice, and recognised that such investigations could have more impact upon rehabilitation than quantitative studies using large but impersonal samples.

Some participants (N=22) expressed confidence that they could apply their learning from the course and redirect their approach to research. Comments from course members included:

"I now understand how to approach a topic from the qualitative point of view."

"I learnt a systematic way to frame research questions."

"It helps me to have a broader look at the research field and motivates me to give more inputs in the field personally."

Participants who had completed research degrees reflected upon their previous learning of research methodology and compared these experiences with the new learning gained from this three-day course. As one stated:

"I realised that the research I undertook for PhD was not up to the mark; after this workshop I look back and see what more could have been done."

Another participant commented that:

"Ethnographic theory was not much explained in our academic settings and hence it (this workshop) helps..." and, "It helped me to expand my knowledge in

the field of research which was covered only in a limited extent in my academic curriculum."

The location of learning within the specific field of disability and rehabilitation was seen as important. The emphasis throughout the course was on instilling a sense of developing qualitative research and an equitable, inclusive and democratic process. This was recognised and appreciated by participants.

"Before this I am not clear where to start my research in inclusive design. Now I can narrow down my topic and I will concentrate on the focus group to identify the samples for the behavioural and user analysis for research study."

"This training is useful as there was no relevant proper training on research methods for a population with disability."

An emphasis upon ethical conduct in research had been given throughout the course, and this had been debated by participants who believed that too little attention has been devoted to this area in some studies. This, in addition to the acquisition of practical methodology applications such as formulating interview schedules, conducting different approaches to observation, conducting focus groups and interviews, and the development of case studies and coding of data, was seen as an important aspect of learning gained through the course.

The application of ethnographic approaches was new to many (N=27) participants. This provoked some to reflect upon the fact that until they understood the value of ethnography they had found it difficult to see themselves as researchers in their own working environment. In one particular instance, a participant working in what might have been seen as a typical environment suited to ethnographic approaches commented:

"Currently, I am doing research with some indigenous tribes in Arunachal Pradesh. Learning achieved from ethnographic research will help me conduct my interview with them."

An interesting observation on this comment is that whilst the participant recognised that ethnography as a broad research methodology was appropriate, the notion of specific interview techniques appropriate to ethnography was unknown prior to completion of this course.

The need to 'think like a researcher', to question and challenge ideas and test theories was appreciated by course participants. As one observed:

“This training programme helped me become critical thinker, to do research in own field. In earlier times I have the motivation to do or think on area to do research. But due to my lack of knowledge I may not be able to do it. But now I feel a bit confident to proceed my thoughts in a more scientific way.”

The course facilitators had throughout the workshops emphasised that their purpose was to encourage practitioners to undertake such research that could promote change and improvements in the lives of individuals with disabilities and their families. At the conclusion of the workshops, course members were asked to reflect upon the actions they might take and to give practical examples of the direction that they may follow as practitioner researchers. It was evident that some had thought deeply about this matter and had already formulated ideas for the application of learning.

“The knowledge gained will be used in my clinical practice to help parents and persons with intellectual disabilities.”

“I had only heard of these and known them only in theory. This workshop has helped me really in getting me hands-on knowledge in using these methods. As we work with children every day, now I am beginning to see the opportunities in the use of qualitative research. I hope to do focus groups for parents of children with similar disabilities (ASD/CP) and also observe a few children on a particular therapy technique.”

In respect of potential improvements to the training, a number of points were raised. Most participants felt that a three-day course was too short and that it should be extended to five days. The course facilitators would generally agree on this point though, as with any course, there are finite resources available to enable this to be realistically achieved.

Some participants felt that they would have liked to spend more time on generating research proposals. This would have enabled them to build upon their learning in a practical manner after the course.

These comments were valid and could be used to shape the thinking of facilitators in the delivery of future training. The general consensus was that the course benefitted from being delivered in a practical manner and the ability of facilitators to provide a clear link between theory and practice through the presentation of exemplars. In addition, the creation of a relaxed teaching atmosphere which gave participants opportunities to engage at their level, was seen as a positive aspect

of the course. In response to the comments on the need for a course of longer duration and the need for more intensive training, a second-level training was organised later, focusing on research proposal generation and data coding and analysis.

DISCUSSION

While much has been written about the importance of researching disability (Brown and Boardman, 2011; Vaccaro, Kimball, Wells and Ostiguy, 2014), opportunities for practitioners to engage in research remain limited (Hardwick and Worsley, 2011; Rose, 2016). In India, disability and rehabilitation research has been dominated by large-scale survey approaches that generate large quantitative data sets that are useful in providing a broad perspective but lack the depth to be of value to clinicians and practitioners (Singal, 2010). Further, Hartley and Muhit (2003) observe that the predominantly quantitative approach to disability research has resulted in a dominance of impairment-related studies and the social aspects of disability have been ignored and under investigated.

Professionals working in the field of disability and rehabilitation are generally involved in practical interventions and procedures, and as such are familiar with learning that takes place in clinical and other work-based settings. The response to the research training course discussed in this paper indicates that the practical elements of the workshops, which afforded opportunities to practice what had been taught during teaching sessions, elicited a positive response from participants. In other studies, it has been reported that much of the professional development provided to professionals in the caring professions in India, has been delivered through largely didactic approaches (Saigal, 2012; Rose & Doveston, 2015). The participants on the courses discussed in this paper confirmed this and emphasised the value of the opportunities provided for debating issues and putting learning into practice.

The tradition of positivistic research that has dominated the field of inquiry in disability and rehabilitation in India has made a significant contribution to knowledge and understanding and will continue to do so in the future (Lakhan & Ekundayò, 2017). However, the authors of the current study contend that as progress from a medico-deficit model of disability to a social model that promotes equity and inclusion continues, it will be important for researchers to provide data that relates immediately to the work of practitioners and the support provided by families and carers. Such research will of necessity require more focused, smaller-

scale studies that generate data to enable understanding of the effectiveness of interventions and the experiences of service users. New knowledge of this type is more easily attained through the application of qualitative research approaches and will require researchers who have specific training in this approach.

CONCLUSION

The findings from the professional development course reported in this paper suggest that there is an enthusiasm for the development of qualitative research skills amongst professionals working in the field of disability and rehabilitation across different parts of India, and there is an opportunity to make considerable advances in this area.

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BRIEF REPORTS

Ground Realities of Autism Spectrum Disorders in Sri Lanka

Nimisha Muttiah*

ABSTRACT

Autism spectrum disorders (ASD) are a group of developmental disabilities that impact children and adults globally. The majority of children diagnosed with ASD live in low- and middle-income countries (LMICs). There is, however, inadequate understanding of the prevalence, screening, diagnosis and treatment for these children in LMICs. As most of the current evidence comes from high-income countries, this narrative review will focus specifically on children with ASD living in Sri Lanka, a lower-middle-income country. It will discuss the prevalence of ASD, current screening and diagnostic assessments, and services available for these children, with a focus on speech therapy and augmentative and alternative communication (AAC).

Key words: *Autism Spectrum Disorders (ASD), Low- and Middle-Income Countries (LMICs), Augmentative and Alternative Communication (AAC), Avaz Sri Lanka*

Autism Spectrum Disorders

Autism Spectrum Disorders (ASD) are a group of developmental disabilities that occur in children, regardless of race or ethnicity. It is a condition that not just low- and middle-income countries (LMICs) struggle with, but also economically advantaged countries (Elsabbagh et al., 2012). The two main aspects impacted in ASD are social communication deficits and restricted and repetitive behaviours (American Psychiatric Association, 2013).

Global Prevalence of ASD

Global estimates of ASD vary among different countries. The most recent estimates from the United States report prevalence rates as high as 1 in 54 children

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(Maenner et al., 2020). Specific estimates of children with ASD living in LMICs are scarce. In general, an estimated 85% of children with disabilities live in LMICs (Helander, 1993); however, these very same countries are under-represented in research conducted on autism (Durkin et al., 2015). Epidemiological data with regard to prevalence of ASD is essential for policy decisions and to strengthen public health practices and services (Elsabbagh et al., 2012).

Prevalence of ASD in Sri Lanka

Sri Lanka has been classified as a lower-middle-income country (The World Bank, 2020). Currently there are only a handful of published and unpublished studies that provide a limited glimpse into ASD and the special education system in Sri Lanka (e.g., Muttiah, Drager, & O'Connor, 2016; Perera, Wijewardena, & Aluthwelage, 2009). To date, only one published study conducted in Sri Lanka gives estimates of the number of children with ASD in the country. It reports a prevalence rate of 10.7 per 1000 children or 1 in 93 children being identified as having ASD (Perera et al., 2009). This is probably a gross underestimation of the actual numbers, as the method used to establish the prevalence rate consisted of a screening tool. In addition, there is evidence referring to the fact that missed or delayed diagnosis of ASD is more prevalent among ethnic and racially diverse groups (Mandell et al., 2009).

Screening for ASD

The American Association of Paediatrics (AAP) has issued a statement that, in general, developmental screenings should be conducted at 9, 18, and 30-month visits, and specific screenings for ASD should be done at 18 and 24 months of age (Hyman, Levy, & Myers, 2020). However, in many LMICs such as Sri Lanka, conducting routine screenings for ASD, as recommended by the AAP, can be complicated for a multitude of reasons. First, agreeing on what types of behavioural characteristics to include in a screening tool is a challenge, as the recognition of a certain behaviour being a deficit can vary among cultures (Wallis & Pinto-Martin, 2008). For example, in a study conducted in Sri Lanka, parents' primary concern was poor development of speech (Perera, Jeewandara, Guruge, & Seneviratne, 2013). Only a small percentage of Sri Lankan parents were concerned about their children's social impairments. In addition, only a small number recognised repetitive, stereotyped behaviours. Secondly, it may not always be appropriate to adapt a screening tool that has been developed in one culture for use by another

(Wallis & Pinto-Martin, 2008). This was evidenced by the translation and use of the Modified-Checklist for Autism in Toddlers (M-CHAT), a screening tool for young children between 18 and 24 months of age. The M-CHAT was translated into Sinhala (the main local language spoken in Sri Lanka). Perera and colleagues (2009) found that when the M-CHAT was used with a group of children in Sri Lanka, it was only 25% sensitive to detect ASD. As a result of the outcomes of this study, a follow-up study was conducted with a view to designing a pictorial screening tool (Perera et al., 2013). The Pictorial Autism Assessment Schedule used photographs to better illustrate the questions that were asked in the checklist. The checklist of items was adapted from the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5), M-CHAT, and “First Signs” from the American Academy of Neurology and the Child Neurology Society. Cultural adaptations were also taken into consideration when developing the tool. Hence, the photographs were of local Sri Lankan children and the items in the checklist were directly written in the local language (Sinhala) rather than translating them from English. The sensitivity of this tool in discriminating between ASD and non-ASD was 88%. However this tool has not been validated, which makes it difficult to use nationally as a screening tool for ASD.

Diagnostic Assessments for ASD

Currently, there are no standardised, norm-referenced ASD diagnostic tools to identify children with ASD in Sri Lanka. The gold standard for diagnosing ASD globally is the Autism Diagnostic Observation Schedule (ADOS-2) (Gotham, Risi, Pickles, Lord, 2006). Clinicians who conduct the ADOS-2 have to be certified and need access to the diagnostic kit with standardised materials. In Sri Lanka, there are less than a handful of professionals certified to conduct the ADOS-2. Both the certification process and the ADOS-2 diagnostic kit are expensive. In addition, some of the items and materials in the ADOS are not culturally and linguistically appropriate. For example, one of the tasks in the Toddler module involves bathing a doll in a bathtub. Many toddlers in Sri Lanka do not have access to a bathtub and are not used to playing with toys while having a bath.

Services

Screening and diagnostic tools to identify the number of children with ASD are useful only if there are corresponding services to support the children identified. In theory, in Sri Lanka, children with ASD have access to speech therapy,

occupational therapy, psychological, and educational services. However, the reality is that these services are only available at larger, urban hospitals in the country. Children living in more rural areas would have to travel to the bigger cities to access such services. Speech therapy has been identified as an essential service for children diagnosed with ASD due to social communication deficits being one of the core deficits (American Psychiatric Association, 2013).

Speech Therapy Services

Speech-Language Pathology is a relatively new profession in Sri Lanka. The first batch of undergraduate speech therapists enrolled in 2008 and graduated in 2012. Currently, approximately 151 Speech-Language Pathologists (SLPs) have been licensed and registered in a country of 20.4 million people (N.R. De Silva, personal communication, August 13, 2018). This indicates that there is approximately one SLP for every 135,000 citizens. This highlights the limited number of professionals who are attempting to provide services to a significant number of children. Professionals are consequently overwhelmed and unable to provide adequate, quality services to all individuals who need them. This has led to the need for innovating methods to provide children and families better access to services. Perera and colleagues reported on a home-based intervention programme that they conducted to deal with this very problem (Perera, Jeewandara, Seneviratne, & Guruge, 2016). Parents were trained on structured play activities and activities to promote joint attention during everyday tasks (e.g., mealtimes). The results indicated positive gains in the children, particularly in the first 3 months after intervention. The findings of this study provide some preliminary evidence in favour of implementing these types of home-based interventions in low-resource settings similar to Sri Lanka.

Augmentative and Alternative Communication (AAC) in Sri Lanka

It is estimated that one-third to half of the children with ASD do not use speech functionally (National Research Council, 2001). Therefore, many of these individuals would benefit from AAC to support their current speech or to act as their primary method of communication (Mirenda, 2003). AAC includes aided technologies, both low (e.g., picture boards, communication books) and high (e.g., speech generating devices, mobile devices), as well as unaided forms of communication (e.g., signs, gestures) (Beukelman & Mirenda, 2013). In countries where there are a limited number of SLPs, the number of skilled professionals

specialising in AAC is extremely small (Fuller et al, 2009). In addition, having culturally and linguistically appropriate AAC options are essential for children with communication difficulties living in these contexts. Although there is a critical need for specialised services such as AAC, currently there is inadequate research conducted on AAC in low- and middle-income countries (Srinivasan, Mathew, & Lloyd, 2011). Therefore, to date, there is only a limited understanding of how best to foster the development of knowledge and skills of individuals who provide AAC support in low- and middle-income countries (e.g., Bornman, Alant, & Lloyd, 2007; Crowley et al., 2013; Muttiah, McNaughton, & Drager, 2015).

In low-resource countries similar to Sri Lanka, the use of low-technology AAC options such as pictures, communication books and communication boards, is common. These AAC options are most appropriate for these contexts as they are readily available in any environment, are low-cost and sustainable. In addition, these can be easily developed and implemented by therapists, teachers and parents.

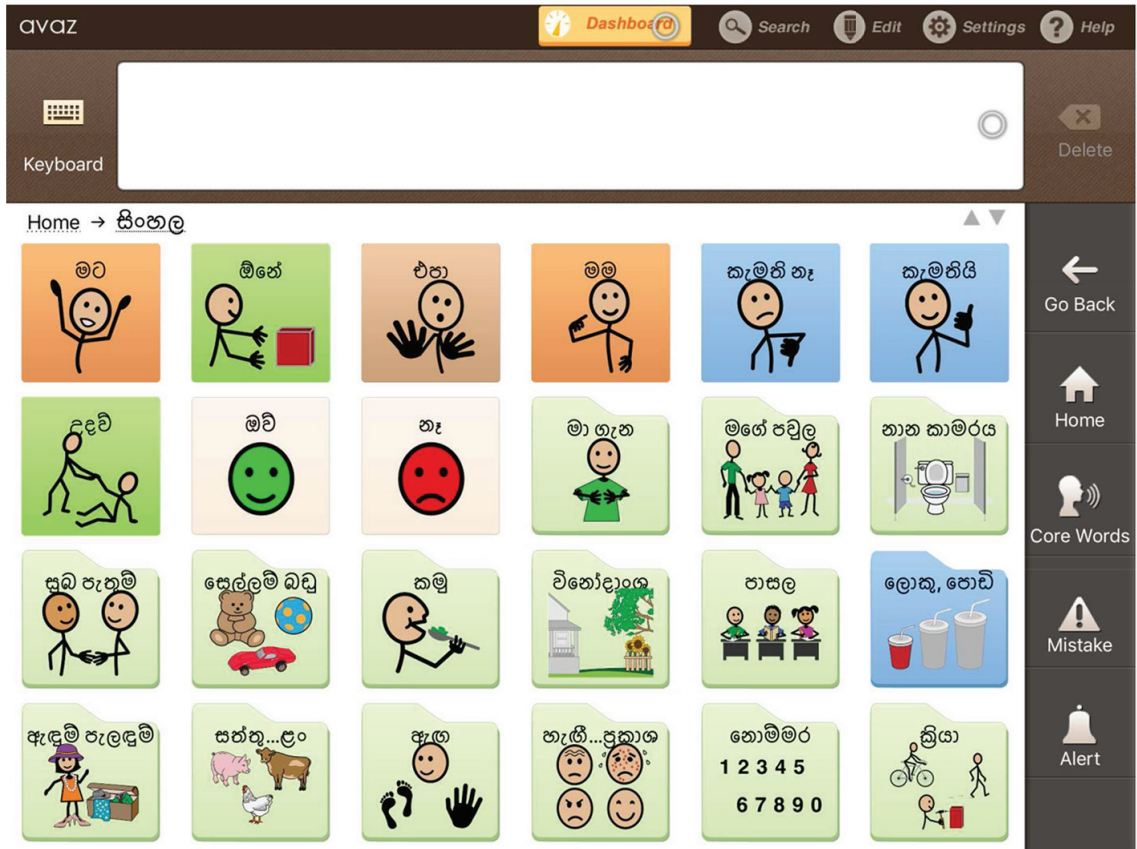
However, the introduction of communication applications on mainstream technologies, such as tablets and mobile phones, has provided new avenues for communication for many individuals with communication difficulties (McNaughton & Light, 2013). Many benefits of using these communication applications have been reported, such as increased functionality (access to education, vocational training and employment) for individuals with communication difficulties (Williams, Krezman, & McNaughton, 2008). In addition, there is a large research base on how the use of such communication applications has resulted in increasing the communication abilities of individuals with communication difficulties (e.g., Ganz, Hong, Goodwyn, Kite, & Gilliland, 2015; Gevarter et al., 2014). These types of communication applications are accessed through a mobile phone or tablet and when children touch the pictures or words on the device, the name of the symbol that was touched is spoken aloud. The speech that is produced through the application is usually digitised speech but many communication apps have options to record a voice as well. For example, if the child wants to eat, he/she can touch pictures/words on the app to say "I'm hungry", or if the child wants to answer a question in school, he/she can touch the communication application to provide an answer. Similarly, an adult with developmental disabilities can use this to communicate with his/her colleagues at his/her place of employment. Individuals with communication difficulties can be

taught to use these communication applications to communicate their thoughts and a variety of messages.

Using these types of high-tech computer-based AAC options may not be viable in low- and middle-income countries. The reasons are the high expenses associated with purchasing a tablet computer or mobile phone, the lack of culturally and linguistically appropriate communication applications to suit the needs of that population (Soto & Yu, 2014), and the limited number of trained clinicians who may be familiar with using these types of AAC solutions (Kieling et al, 2011). However, there is a small but growing body of evidence demonstrating success in the use of these types of high-tech AAC options in low- and middle-income countries (e.g., An et al., 2017; Genc-Tosun, D., & Kurt, O., 2017; Tönsing, 2016).

In November 2017, the first communication application developed in Sinhala and Tamil (local languages), Avaz Sri Lanka, was launched in the country (Muttiah, 2018). Avaz Sri Lanka allows children with severe communication difficulties, including those with ASD, to express their needs and wants, build social relationships, and participate in education and society. More research is needed on this communication app to identify its compatibility with the development of typical language, to gauge children's success with learning to use this app, and assess how easily therapists, teachers and parents can be trained to facilitate using the app with children who have communication difficulties (see Figure 1).

Figure 1: Avaz AAC for Sri Lanka (a screenshot of the application)



In Conclusion

The path for children with ASD and their families in Sri Lanka has not been easy. However, in the past decade there has been a significant increase in awareness of ASD, with more children accessing services, an increased number of healthcare workers intervening with these individuals, more schools accepting children with ASD, increased access to AAC solutions (e.g., Avaz Sri Lanka) and a growing body of research on ASD in Sri Lanka. The road ahead is still challenging for these children and their families. However, the achievements of the past 10 years should give them hope and should inspire clinicians and researchers to do more on their behalf. The journey ahead is long and arduous but positive strides are being made.

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Healthcare-seeking Behaviour among Working Women with Disability in Karnataka, India

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ABSTRACT

Purpose: In India women constitute 44% of the total population with disabilities, which roughly amounts to around 10 million persons. This study explores healthcare-seeking behaviour among working women with disabilities in the country.

Method: A cross-sectional study using a quantitative survey was conducted among 72 working women with disability to explore their patterns of health-seeking behaviour. Women with disability, between 18 and 45 years of age, who were currently working full-time and who had experienced a serious health problem in the past year were included in the study. A pre-structured questionnaire was used for the survey.

Results: Body pain (78%) followed by Urinary Tract Infections (9%) were the commonly cited health problems by the study participants. Eighty percent (80%) of women with disability sought care for their health issues. The actions that they took for their health problems depended on the severity of the disability (p -value-0.001), type of the disability (p -value-0.05), marital status (p -value-0.035) and savings (p -value-0.042) they had set aside for themselves. Monthly family income and years of disability showed correlation with the type of care that they opted for.

Conclusion: Employed women with disability show a positive healthcare seeking behaviour pattern. The action they take in addressing their health issues and the type of care that they opt for depends on factors associated with their disability, decision making capacity and financial stability or savings.

Key words: healthcare-seeking behaviour, women with disability, healthcare, access to health-care, employed women, disability

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INTRODUCTION

According to the Census 2011, there are around 10 million women with some kind of disability in India (Government of India, 2016). Yet, very little is documented about these women with disability and their life events. Their special needs, concerns and issues are seldom addressed. Be it at the individual, family or community level, women with disabilities tend to be ignored, discriminated and abused (United Nations, 2017). This lack of autonomy can affect their decision-making capability, especially in seeking healthcare.

Healthcare-seeking behaviour is a complex phenomenon especially when it comes to persons with disability. Healthcare-seeking behaviour is defined as “any action undertaken by individuals who perceive themselves to have a health problem or to be ill for the purpose of finding an appropriate remedy” (Olenja, 2003). It is affected by various geographical, social, individual, economic, cultural, political and cognitive factors which are dependent on availability, accessibility, affordability, adequacy and acceptability (Mackian, 2002). In general, it is thought that healthcare-seeking behaviour is more prevalent among people with disabilities, probably because of their greater and often more complex healthcare needs in general (Patel, 2007). A study conducted in 2 districts in South India suggests that people with disabilities (18.4%) visit a hospital significantly more often as compared to people without a disability (8.8%), and they are 5.1 times at higher risk of being hospitalised at any time as compared to people without a disability (Gudlavalleti et al, 2014). Globally, a study done by the World Bank estimated around 80% of healthcare utilisation among people with disabilities (World Health Organisation, 2011). However, women with disability are less likely than men with disability to seek treatment. They are 13% less likely to receive assistive devices as compared to their male counterparts (Moscoso-Porras & Alvarado, 2018). Ignorance regarding availability of services, costs of services and inadequate and inaccessible transportation are some of the frequently reported barriers in decreased utilisation rates (Padhyegurjar & Padhyegurjar, 2012). Age, level of autonomy, social factors, and physical limitation could also play a significant role in reduced healthcare-seeking behaviour among women with disability. On the other hand, factors such as employment and autonomy are known to reduce gender disparities, thereby contributing to social inclusion and empowerment, especially for women.

Employment, autonomy and health are interlinked. Employment is a gateway to autonomy, which empowers women to take decisions relating to their personal

concerns independently. Several studies prove that healthcare-seeking behaviour is significantly improved with increased levels of autonomy, especially among women. (Senarath & Gunawardena, 2009; Nayak & Varambally, 2017). A systematic review of European Union and OECD countries on social exclusion and health published in 2018, states that there is an association between the two. The experience of exclusion like low social status, feelings of alienation and lack of belongingness has a direct impact on both physical and mental health and well-being (van Bergen et al, 2019).

However, in the context of disability, the representation of women with disability in the work force remains unclear. The Indian Government reserves 3% of government jobs for people with disabilities, and also provides incentives for private sector companies to employ them. But these rights and entitlements are rarely availed of by private companies or by persons with disabilities, especially by women with disability (Shenoy, 2011).

Though there are studies that look into healthcare-seeking behaviour of persons with disabilities there is hardly any literature exploring the healthcare-seeking patterns of working women with disability in India. Healthcare-seeking pattern may or may not be different for a working woman with a disability and the health-related issues faced by them could be different because of a pre existing condition. Exploration into the factors that affect their health-seeking pattern and the type of care that they opt for may contribute to making existing health care policies disability-friendly and gender-sensitive at the same time.

Objective

This study was conducted to examine the patterns of healthcare-seeking behaviour among working women with disability, between 18 and 45 years of age, engaged in full-time employment in or around Bangalore and having experienced at least one health problem in the past one year.

METHOD

Setting

The study was conducted at The Association of People with Disability (APD), in Bangalore city, India. APD is a 60-year-old NGO which aims to contribute to the transformation of lives of people with disability. A job readiness course is offered

as a foundation course by APD, to equip persons with disability for employment in line with their functional capabilities, aspirations and support systems. Several women with disability get enrolled in this programme every year.

Sample

Convenience sampling was used, as the study focused specifically on women with disability who were employed. Records of women with disability who had undergone the foundation course from 2015 to 2017 and were working in or around Bangalore, in Karnataka, were used to select the study sample.

Inclusion criteria were:

- Working women with disability, 18 to 45 years of age;
- Currently engaged in full-time employment;
- Having enrolled in the foundation programme during the years 2015 to 2017; and
- Having experienced at least one serious health problem in the past year.

Excluded were:

- Women with severe disability, pregnant women or women working part-time.

Around 198 women with disability were identified for the study. Among them, around 110 women satisfied the inclusion criteria. Of the 110 women with disability, 72 women consented to participate in the study.

Informed written consent was taken from the participants.

Study Tool

A structured interviewer-administered questionnaire was used for data collection. The questionnaire was developed based on a literature review and was divided into four sections. The first and the second sections consisted of general information i.e. one related to demographic and the other on socioeconomic status of the participants, including age, marital status, education level, monthly income and other variables (see Table 1). The third section focused on details related to the disability and the final section focused on healthcare-seeking behaviour in terms of the number of health problems faced by the interviewee in

the past year, actions that were taken and the various factors that could affect the actions that were taken.

The questionnaire was reviewed by two experts in the field of disability and rehabilitation. It was then piloted among 15 women with disability who were employed by APD prior to the actual study and, as such, were not part of the study population. The questionnaire was translated into Kannada and back translated in order to prevent errors in the final target language and for the ease of administration. Both English and Kannada questionnaires were used in the study.

Data Collection

The data collection was done with the help of 4 community workers. Data collectors underwent one day of training on the questionnaire survey technique.

Data Analysis

The data was coded and analysed using SPSS (version 18.0) for descriptive statistics. Descriptive statistics including frequencies and percentages were used for data analysis. Chi square test and Pearson's correlation were computed to find the associations with the healthcare-seeking behaviour. The p-value of <0.05 with a confidence level of 95% was considered significant. A correlation analysis was also done to find the factors that determined the type of care that women with disability opted for in the event of a health issue.

RESULTS

Seventy-two (72) women participated in the study. The majority of the participants (60%) belonged to the age group of 18 to 25 years and about half (52%) of them had an educational qualification lower than class 10 of high school. About 76% of the participants had a locomotor disability, followed by 16.9% with a speech and hearing disability. The majority of women had office jobs and 54% stated that their family income was less than Rs.10,000 (136 USD) per month. A few were also the sole breadwinners of their families. Table 1 provides details about the demographic profile of the study participants.

Table 1: Demographic Profile of Women with Disability who Participated in the Study

No.	Variables		Frequency (n)	Percentages (%)
1	Age	18 to 25 years	43	60.3
		26 to 35 years	23	32.2
		36 and above	6	9.8
2	Educational status*	Illiterate	2	2
		Less than high-school	36	51.4
		Standard 10	5	7.1
		Pre-university	13	18.6
		University Degree/ Diploma	10	14.3
		Post-Graduate and above	4	5.7
3	Type of disability*	Locomotor	54	76
		Visually Impaired	3	4.2
		Speech and Hearing	12	16.9
		Others	2	2.8
4	Years with disability*	By birth	41	56.16
		Less than 5 years	18	24.65
		6 to 10 years	4	5.47
		More than 10 years	7	9.58
5	Family Income*	Below 5000	30	42.3
		5001-10,000	22	31
		10,001-25,000	18	25.4
		25,001 and above	1	1.4
6	Is there a healthcare facility near your house?*	Yes	37	57.4
		No	33	45.8
7	Is there a healthcare facility near your workplace?*	Yes	32	46.4
		No	37	53.6

8	Does your work area consist of a health clinic?*	Yes	31	43.1
		No	40	55.6
9	Usual mode of travel*	Walk	18	24.65
		Own / Private vehicle	3	4.1
		Public transport	42	57.53
		Company vehicle	3	4.1
		Others	5	6.84

* Frequency (n) corresponds to only participants who responded. Therefore, the total does not add to 72.

Body pain followed by urinary tract infections were the most commonly reported health problems. Nearly 80% of the women with disability stated that when they experienced a health problem, they took action and consulted healthcare professionals. This denotes good healthcare-seeking behaviour among women with disability. Nearly 87% stated that they sought care immediately or within 2 days after identifying their health problem. Three-fourths of the participants approached government hospitals rather than private hospitals, clinics or traditional medical centres. Among the participants who reported delayed response in seeking medical attention for their ailments, the most commonly given reason was lack of time. Government hospitals were generally the preferred choice of healthcare facility as compared to private hospitals.

Regarding access to healthcare, a majority (57%) of the participants stated that there was a healthcare facility located near their homes. Nearly 53% reported no healthcare facilities close to their workplace. More than half of the interviewed women used public transport as their preferred mode of travel to their workplaces or health centres.

Common barriers faced by working women with disability in their workplaces included lack of accessible toilets, unpaid excess working hours and schedules, and inadequate opportunities to take leave to look after their health needs.

“I don’t drink enough water such that I don’t have to go to the washroom which is not accessible. I have got urine infection several times...”

“We do not have disability-friendly environment, no health clinics are conducted in our working place...”

"We are forced to do extra duties with no extra pay."

The women also pointed out that public hospitals are in fact unfriendly places for people with disabilities. The commonly-listed issues related to public hospitals were long waiting hours, non-availability of medical doctors, inaccessible hospitals and, in addition, negative attitudes. As expressed by one of the interviewees,

".....we are neglected most times".

Bivariate analysis explored the factors that affect their decisions to seek care for their health problems and the type of care they opted for (Table 2). It showed that the actions taken in relation to their health problems depend on the severity (p value-0.001) and type of the disability (p value-0.052), marital status (p value-0.035) and the savings (p value-0.042) they had kept aside for themselves. There was better response among women with milder form of disability, were single or had a better financial stability in form of savings. Correlation analysis to identify factors that determined the type of care which the women opted for showed that monthly family income and years of disability to have highly correlated with the type of care opted for in the event of a health issue. It was noted that women with lower monthly income or with a higher duration of having lived with a disability opted more for Government facilities.

Table 2: Factors affecting Decisions to Seek Care and the Type of Care opted for

No.	Variable		What did you do for your health problem?		P value
			Action Taken	Action not taken	
1	Status of the disability	Mild	19 100%	0 0%	0.001
		Moderate	33 86.8%	5 13.2%	
		Severe	5 41.7%	7 58.3%	
2	Type of disability	Locomotor	48 88.9%	6 11.1%	0.052
		Visual	2 66.7%	1 33.3%	
		Speech and Hearing	7 58.3%	5 41.7%	

	Others	2 100%	0 0%	
3	Do you keep some money aside for yourself from what you earn?	Yes 46 86.8%	7 13.2%	0.042
	No	11 64.7%	6 35.3%	
4	Marital status	Single 15 100%	0 0%	0.035
	Married	42 77.8%	2 22.2%	
	Divorced	0 0%	1 100%	
	Separated	1 100%	0 0%	

DISCUSSION

Health-seeking behaviour is a complex phenomenon. There are a limited number of studies specifically looking into healthcare-seeking patterns of working women with disability. A study done in Bangladesh states that working women are 1.7 times more likely to seek healthcare as compared to non-working women (Hasan & Uddin, 2016).

Employment and autonomy are thought to play a crucial role in women's attitudes towards their health issues. Autonomy is the power to obtain information and arrive at decisions about personal concerns (Dyson & Moore, 1983). Women's control over resources, their decision-making power and freedom of movement tend to influence their attitudes towards health and healthy habits. The women who participated in this study were from different parts of Karnataka State and had migrated to Bangalore city to work. They lived in working women's hostels or as paying guests in different parts of the city. A majority of them were independent women travelling to work and other places by bus and other public transport systems. They had some money kept aside for themselves as savings. The majority of them took appropriate action for their health concerns within the first two days of recognising symptoms of illness and approached qualified healthcare professionals at a healthcare facility. They also preferred to consult qualified doctors at government hospitals for their treatment. This study shows

that the majority of women with disability, in spite of a variety of disabling factors that they face, lead independent and autonomous lives. Empowerment gained through the widened network at their workplaces and the society they live in could have influenced their ability to seek health information and health-care.

The study shows that severity of the disability, personal savings and marital status play a role in determining the healthcare-seeking pattern among women with disability. The milder the disability and the more the savings that women have, the better is their healthcare-seeking behaviour. A study done in Cambodia stated that persons with disabilities were less likely to draw upon income and savings and more likely to draw upon support from relatives in order to finance healthcare-related expenses than persons without disabilities (World Health Organisation, 2017). The present study in Karnataka, which focused on employed women with disability, suggests that once they are employed and possess savings, they are ready to invest in their health and healthcare needs. Though the majority of women who participated in the study were married, our results indicate that women who are single showed better healthcare seeking pattern. Generally, married people are thought to have an advantage because they have someone to support, remind or help them with seeking care. However, the majority of the working women who participated in this study migrated from different parts of Karnataka to live in hostels or as paying guests in cities or in areas where there are better employment opportunities and adequate public support systems. Better support systems along with a better decision-making freedom could thus be important determinants and influence both married- but even more single women with disability to seek earlier and more appropriate support from health care services.

Patel (2007), in a study done in India, found that perceptions about health problems and the need to make use of healthcare services play an influential role in treatment-seeking behaviour. The majority of the working women in this study suffered from back pain and urinary tract infections. This could be due to their long working hours, improper posture due to poor seating arrangements or overtime work which they complained about. According to some participants, inaccessible washrooms made it difficult for them to use frequently. This could be a factor predisposing them to develop urinary tract infections. The majority of working women with disabilities stated that there were no health clinics at the workplace or nearby which they could utilise for their work-related health issues.

The sound healthcare-seeking behaviour observed in this study could be because of the women's increased social interaction with others through their employment. However, more research is warranted to further explore the relationships between health and the employment status of women with disabilities in India.

CONCLUSION

Working women with disability show, in general, sound healthcare-seeking behaviour. Severity of the disability, personal savings, marital status, years of disability, and decision making capacity were a few of the factors that influenced the healthcare-seeking behaviour and type of healthcare accessed. Employment and decision making capacity could be one of the underlying reasons for the good health status enjoyed by these women with disability.

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* * * * *

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