



DISABILITY, CBR & INCLUSIVE DEVELOPMENT

Formerly Asia Pacific Disability Rehabilitation Journal

Volume 32 ■ No. 2 ■ 2021

Contents

EDITORIAL : Speak Less but Act More

Huib Cornielje 3

ORIGINAL RESEARCH

Experiences of Persons with Disabilities and their Quality of Life in Two Namibian Villages

Tonderai Washington Shumba, Indres Moodley 6

An Unclear Task?

Perspectives of Swedish Preschool and Special Needs Teachers on their Role in Assessing and Documenting Child Development

Maja Erlandsson, Christina Gustavsson, Peter Karlsudd..... 30

Cross-Cultural Adaptation and Validation of the Fatigue Severity Scale among Kannada-speaking Individuals with Neurological Disorders: A Cross-Sectional Study in South India

Akhila Jagadish, Manikandan Natarajan, John Solomon M 51

Socioeconomic Factors Hindering Access to Healthcare by Persons with Disabilities in the Ahanta West Municipality, Ghana

Henry Abuaku Howard, Anastasia Baisiwa Rhule 69

Challenges Associated with Vocational Rehabilitation for Persons with Disability in the Kumasi Metropolis of Ghana

Enoch Acheampong, Godfred Atta-Osei, Alberta Nadutey, Peter Bredu-Darkwa, Gloria Boateng 88

Employment Needs of Young Adults with Visual Disability need to be Recognised in Kabul, Afghanistan

Fahima Ibrahimkhil, Freba Amarkhail, Suriati Sidek 104

Efficacy of the Smartphone App for sending Text Reminders to reduce 'No Shows' in Speech Therapy Sessions at a Tertiary Care Centre in India

Md Noorain Alam, Sanjay Munjal, Naresh Panda, Manisha Garg, Mannat Kaur Shipra 127

Does Residing in Environments of Different Metropolises in a Developing Country have an Impact on Disability after Stroke?

Soraia Micaela Silva, Fredi Alexander Diaz-Quijano, Camila Ferreira da Cruz, Paula da Cruz Peniche, João Carlos Ferrari Correa, Christina Danielli Coelho de Morais Faria 142

REVIEWS

Self-Advocacy and Ally-Advocacy for Disability Justice: Organisational, Psychosocial, and Political Resources

Henry McCarthy 160

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Website: www.dcidj.org

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580, K.R. Garden, Koramangala, Bangalore - 560 095, India.

Tel : 91-80-25710658 Email: nppbangalore@gmail.com



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CONTENTS

Volume 32 ■ No. 2 ■ 2021

EDITORIAL : Speak Less but Act More

Huib Cornielje 3

ORIGINAL RESEARCH

Experiences of Persons with Disabilities and their Quality of Life in Two
Namibian Villages

Tonderai Washington Shumba, Indres Moodley 6

An Unclear Task?

Perspectives of Swedish Preschool and Special Needs Teachers on their Role in
Assessing and Documenting Child Development

Maja Erlandsson, Christina Gustavsson, Peter Karlsudd 30

Cross-Cultural Adaptation and Validation of the Fatigue Severity Scale among
Kannada-speaking Individuals with Neurological Disorders: A Cross-Sectional
Study in South India

Akhila Jagadish, Manikandan Natarajan, John Solomon M 51

Socioeconomic Factors Hindering Access to Healthcare by Persons with
Disabilities in the Ahanta West Municipality, Ghana

Henry Abuaku Howard, Anastasia Baisiwa Rhule 69

Challenges Associated with Vocational Rehabilitation for Persons with Disability in the Kumasi Metropolis of Ghana <i>Enoch Acheampong, Godfred Atta-Osei, Alberta Nadutey, Peter Bredu-Darkwa, Gloria Boateng</i>	88
Employment Needs of Young Adults with Visual Disability need to be Recognised in Kabul, Afghanistan <i>Fahima Ibrahimkhil, Freba Amarkhail, Suriati Sidek</i>	104
Efficacy of the Smartphone App for sending Text Reminders to reduce ‘No Shows’ in Speech Therapy Sessions at a Tertiary Care Centre in India <i>Md Noorain Alam, Sanjay Munjal, Naresh Panda, Manisha Garg, Mannat Kaur Shipra</i>	127
Does Residing in Environments of Different Metropolises in a Developing Country have an Impact on Disability after Stroke? <i>Soraia Micaela Silva, Fredi Alexander Diaz-Quijano, Camila Ferreira da Cruz, Paula da Cruz Peniche, João Carlos Ferrari Correa, Christina Danielli Coelho de Morais Faria</i>	142

REVIEWS

Self-Advocacy and Ally-Advocacy for Disability Justice: Organisational, Psychosocial, and Political Resources <i>Henry McCarthy</i>	160
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Editorial: Speak Less but Act More

“The best way to find yourself is to lose yourself in the service of others”- Mahatma Gandhi.

The disability world globally, together with many INGOs active in the field of disability, have – rightfully – been focussing their activities on lobby and advocacy for equalisation of opportunities and full inclusion of people with disabilities in all spheres of life. These efforts have indisputably and significantly contributed to the position of people with disabilities in many parts of the world. It resulted in – at times – new commitments to address the serious inequalities that exist in the world. However, it is also obvious that the euphoria of the past 20 years or so that culminated in the adoption of the UN Convention on the Rights of Persons with Disabilities (UNCRPD) in 2007 and subsequent ratification of the UNCRPD of many national states, including those who are openly or less openly have a track record of gross violation of even the most basic human rights of its civilians, has often not resulted in any significant change in the lives of the poorest of the poor. Those who live in the slums and remote rural areas of many countries have not yet seen any change in their lives and that of their families. One can call me cynical, but this is the sheer reality for still hundreds of thousands of people in low- and middle-income countries. They live in a reality in which one cannot do anything but try to survive. Such people are not seen by corrupt or not so corrupt politicians (disabled or not), but rather are regarded as useless people who are not worthy to invest in.

I am now editor-in chief of this great journal for one year. But do all the articles that have been written in the past year truly contribute to a better life, better acceptance, better opportunities for those people who are often the subject of our writings? After one year of my editorship, I received a handful comments by readers and that is worrying me. Do we only have time to write more manuscripts but forget to read? And when we are reading, do we read about the real situation on ground? Do we read about successes in overcoming the political battles; the attitudinal barriers and the simple fact that so many people with disabilities have no access to even the most essential services they need? I am aware that providing services is not so sexy but in essence, is that not often what the poor mother of the child with microcephaly in a day care centre of a refugee camp on the coast needs? And is the fact that a smart, 12-year-old athetoid child with cerebral palsy who is just sitting in a day care centre, getting old-fashioned therapy in

the form of passive exercises for many without knowing what for, not being intellectually stimulated, not a missed opportunity for that child but also a sign a failure from the side of the government as well as the INGO sector? These are just a few examples of thousands of children in a country which I recently visited, and which was among the early ones that ratified the UNCRPD, has inclusive legislation and policies in place but fail to serve those who need to be served for the past decades.

During my recent and first assignment this year in that African country, I felt depressed with the fact that so many people talk about inclusion; that training of rehabilitation professionals seem to be especially based on western and international criteria and standards but is hardly contextualised and mainly theoretical and for many, a steppingstone for a decent personal life only. I am worried about the lack of access to services for the poor as well as the poor quality of services which seem to even be harmful at times. I am, however, even more concerned about the fact that those who are in power (politically and academically) seem not to be aware of this; may deny this or have no interest in changing this. And what about the international development community of whom many have been working in that part of the world? Did they play a role in the lip service paid which one literally notices?

I realise that I am asking many critical questions but who to blame? Or better what to do? Should we invest in just more awareness raising activities and just more lobby and advocacy? Or is it time to be genuine and realistic, look into the mirror and conclude that we are failing those who didn't benefit from progressive legislation but also not from inclusive policies and programmes? Will all the new grand policies coming from the ivory towers of various origins and capitals of western societies bring the much-required changes? Or will it be the usual rhetoric with new terminology and strategies which have been tried in the past and keep us intellectuals to remain in power?

It is time for reflection and taking stock of what we do. Possibly, it is time that we start using all our senses and listen to those who so far were the ones that are least listened to; to talk with those we usually don't talk with; to spend more time in the field and less time in the office; to look for contextualised developments instead of promoting standard approaches to situations that require non-conventional interventions. May I challenge you to submit papers that deal with the not so good practices; may I challenge you to write about your concerns but also about much needed suggestions in ensuring that this world become a bit a better place

for all. This journal allows you to write letters to the editor and I am inviting you once again to share your ideas; innovative ones and not so innovative ones but ones that will add knowledge and which will inspire us as readers (academics and practitioners) to do our work better and ensure that there is impact in what we are doing.

Finally, during the aforementioned assignment, we came across a frontline worker who is running a day care centre for children with neuro-developmental disabilities without any salary. She learned while working with the caregivers of those children that rehabilitation is much more than giving therapy. She learned that one can be bothered about ways to feed a child with cerebral palsy but if the family is not having access to food, the provided adapted chair and instructions to the mother about handling and positioning of the child while feeding become easily futile. She thus made sure that the programme also focusses on socio-economic development. Such a person is a hero. Such people are the ones making a real difference in the lives of people. Such people don't talk the politically correct language but instead do the work that needs to be done and are glimmers of hope.

Huib Cornielje
Editor-in-Chief
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ORIGINAL RESEARCH

Experiences of Persons with Disabilities and their Quality of Life in Two Namibian Villages

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ABSTRACT

Purpose: *The study aimed to determine the convergence and divergence of the Photovoice method and the WHOQOL-BREF assessment in integrating the experiences of persons with disabilities with Community-Based Rehabilitation (CBR) and their quality of life respectively. It also aimed to propose a practice framework for CBR programme evaluation in Namibia.*

Method: *A qualitative phenomenological design was utilised. Twelve participants were part of this study. The primary data sets used for analysis were photographs taken during a study using the Photovoice method and the results from the WHOQOL-BREF questionnaire. The Photovoice process preceded completion of the WHOQOL-BREF questionnaire. Information about the participants was gathered during the two phases. The CBR Matrix developed by the World Health Organisation was utilised to determine themes for the Photovoice method. Results of the Photovoice study were integrated with those of the WHOQOL-BREF to determine convergence and divergence.*

Results: *Notably, most participants (n=8) in both study sites had low scores regarding their quality of social relationships and environment. Furthermore, the Photovoice method revealed negative experiences of the participants regarding the environment (physical safety and security, home environment, financial resources, health and social care, access to information, recreation and leisure, physical environment, and transport). By and large there was a stronger convergence than divergence of the Photovoice method and WHOQOL-BREF assessment.*

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Conclusion and Implications: *Notwithstanding the in-depth investigation, the small sample size limits generalisability of the research findings. A study with a larger sample size is needed to confirm the findings, especially regarding the WHOQOL-BREF assessment.*

This study proposes a practice framework for CBR programme evaluation in Namibia that integrates the WHO CBR Matrix, Photovoice method, WHOQOL-BREF and highlights from the other frameworks. Further studies are required to validate the framework.

Key words: *Photovoice, WHOQOL-BREF, persons with disabilities, CBR evaluation, Namibia*

INTRODUCTION

Community-Based Rehabilitation (CBR) in Namibia was initiated in 1992 (Ministry of Health and Social Services, 2013) and officially adopted in 1997 as the main strategy for disability inclusion and rehabilitation (Government Republic of Namibia, 1997). Since then, the CBR programme has been evolving in line with global disability trends. Namibia has made significant progress in CBR monitoring and evaluation. However, CBR evaluation in Namibia is dominated by conventional quantitative methods.

Although low literacy rates amongst persons with disabilities have been reported in both low-income and high-income countries, it is more pronounced in poorer countries and thus poses a challenge on CBR evaluation frameworks which require high levels of literacy (WHO & World Bank, 2011). Furthermore, in some southern African countries (Namibia, Malawi, Zambia, Zimbabwe) between 24% - 39% of children aged 5 years and older, with disabilities, have never attended school (WHO & World Bank, 2011). To this end, there is a need to investigate mixed evaluation research methods: methods that are complementary and methods which require the participation of persons with disabilities in the evaluation process.

Against the backdrop of mixed-method CBR evaluation, the authors of this study undertook to develop and propose a monitoring and evaluation framework that could be used to assess lived experiences of persons with disabilities regarding their quality of life. Preparatory phases to develop this framework involved a number of investigations to provide a comprehensive background as outlined below.

A review of policies and legislations in Namibia (Shumba & Moodley, 2018a) identified CBR as underpinning key strategy for delivery of disability and rehabilitation services in the country. Shumba and Moodley (2018b) also confirmed the need to explore the experiences of persons with disabilities in CBR programmes using appropriate qualitative evaluation tools. A scoping review established that Photovoice has the potential to be utilised as a qualitative evaluation tool for effectively eliciting the experiences of persons with disabilities on a CBR programme (Shumba & Moodley, 2018c).

Photovoice is a method that can be used by vulnerable populations including persons with disabilities to voice their concerns and enable them in their advocacy efforts, and as such better reach policy-makers. Vulnerable populations use photographs captured in Photovoice to facilitate interpretation of community concerns and this promotes policy change (Wang & Burris, 1997). However, Photovoice has evolved since its initial conceptualisation and has extended to be used as a qualitative research tool for many purposes including a participatory evaluation tool, a retrospective evaluation method (Kramer et al., 2010) and a needs assessment tool (Findholt, Michael & Davis, 2011).

Although Photovoice has the potential to elicit the experiences of persons with disabilities, it does not provide a measure for quality of life. To this end, the World Report on Disability recommended evaluation tools that can simultaneously measure the experiences of persons with disabilities and their quality of life.

'To understand the lived experiences of people with disabilities, more qualitative research is required. Measures of the lived experience of disability need to be coupled with measurements of the well-being and quality of life of people with disabilities' (WHO & World Bank, 2011).

Thus, to confirm the elicited experiences of persons with disabilities, the measurement of quality of life becomes critical. A number of instruments can measure the quality of life for persons with disabilities. One relevant instrument is the Quality of Life (WHOQOL) instrument (WHOQOL Group, 1995) developed by the World Health Organisation, and intended to assess people's 'perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns' (World Health Organisation, 1998). It can be used to establish (baseline) scores in a range of areas including effectiveness of treatments, audit, policy-making, and research. Furthermore, it can be utilised to determine changes in quality of life

during the course of interventions, research, and policy-making (World Health Organisation, 1998). The WHOQOL instrument has two forms: the WHOQOL-100 with 100 questions of assessment and the WHOQOL-BREF with an abbreviated 26-item assessment. The WHOQOL-BREF is used when there is a group of participants who do not have enough time and should not be over-burdened. Both instruments have various domains and sub-domains to produce a multi-dimensional profile of scores including environmental, psychological, physical health and social relationships. In addition to the above-mentioned quality of life domains, the WHOQOL-BREF measures other aspects including the quality of sexual life, which in most instances is not measured with other instruments. WHOQOL-BREF was developed in 29 language versions, embracing 15 cultural settings (World Health Organisation, 1998).

A feasibility study (Shumba & Moodley, 2018d) was conducted to assess the potential of utilising the WHOQOL-BREF questionnaire following the Photovoice method to quantitatively assess the baseline quality of life of persons with disabilities. This study (Shumba & Moodley, 2018d) identified critical issues to be considered in the implementation of future studies, utilising a combination of Photovoice and the WHOQOL-BREF. These refer to four broad feasibility criteria of classifications, i.e., process, resources, management, and scientific processes, as mentioned by Van Teijlingen et al (2001) in a study done to establish the rationale of feasibility studies. These four feasibility criteria are crucial in mapping key requirements for future main studies. A detailed explanation of each feasibility criteria is provided in Table 1.

Table 1: Study Criteria

Criteria	Issue assessed	Lessons learnt in feasibility study by Shumba and Moodley (2018a)	Final criteria for current study
1. Process: Assessing the feasibility of the processes that are key to Photovoice and WHOQOL-BREF assessment	Study site - CBR programme	The CBR volunteers who participated were active and helped in identifying and motivating other participants	-Functional CBR committee and CBR volunteers with at least 2 years of CBR programme implementation were selected -Two different geographical study sites were selected to ensure diversity in terrain, culture and tribal influence

	Participant characteristics	Including caregivers/family members/siblings of persons with disabilities gives skewed perspectives of experiences and quality of persons with disabilities. Furthermore, persons with mental illness and intellectual disabilities require rigorous selection and particular attention to ethical processes	-Included: people with physical disabilities, able to use a camera and describe/explain a picture, willing to remain involved in the study for one month -Excluded: caregivers/family/siblings of persons with disabilities, persons below 18 years of age, intellectual disabilities, mental illness, highly dependent on medical care, HIV positive and previous traumatic war experiences or stressful life circumstances
	Research assistant	Persons with hearing impairment were excluded from the study as both researcher and research assistant had no sign language skills	Senior Rehabilitation Officer for each region was selected as follows: -Have at least 3 years of CBR experience -Have been working for at least 2 years in CBR programme in that region -Able to speak the local language of that area -Well-versed with local culture -Have basic sign language skills.
	Retention of participants	Retention rate was 6 out of 9 (66.67%). Reasons for drop out were lack of incentives and poor communication with research assistant	- Availied of airtime for group leader of participants for constant communication with researcher and research assistant -Certificates of completion and non-monetary incentives including T-shirts were given
	Understanding the data collection tools - Photovoice technique and WHOQOL-BREF	- Though explained by researcher, the research assistant's understanding of Photovoice method and WHOQOL-BREF was poor	- Research assistants trained and oriented on the Photovoice method and WHOQOL-BREF before selecting participants
	Adherence to Photovoice ethical issues	- Participants had challenges of getting signatures for providing consent to take photographs of human subjects - most of the participants and subjects could not read and write	-Subjects to be photographed or their caregivers provided an "X" as indication of signature and then the researcher/ research assistant followed up these subjects to confirm consent
2. Resources: Forecast time and resource problems that can occur during the main study	Process taking photos and having to share their thoughts about the photos	-Some participants took time to recall why they took the photo because of the time lag in processing the cameras and interviewing	-Disposable cameras were processed immediately after photography assignment and interviewing was done within 2 days
	Establish time needed to fill out the WHOQOL-BREF questionnaire	-It took roughly 40 minutes to an hour for filling out the WHOQOL-BREF questionnaire as participants needed to be assisted -Participants were already tired of filling the WHOQOL-BREF questionnaire following the Photovoice interview	-A break was taken between Photovoice interviewing and filling out the WHOQOL-BREF questionnaire

	Type and quantity of language version of the WHOQOL-BREF questionnaires needed	-Most participants could understand well the Afrikaans WHOQOL-BREF version	- Copies of both the English and Afrikaans versions were printed
	Place and cost of Braille or large print questionnaires	-Braille material was not available for one participant with visual impairment and thus relied on interpretation	-A resource centre was asked to provide Braille documents for blind and visually impaired participants
	Type of camera to use	-Disposable cameras allowed participants to take a limited number of photographs, these cameras are strong and cheap to purchase -Place for processing the cameras (film) was easily accessed -The quality of some pictures taken was fair	-Disposable cameras were ideal in rural settings -Established the proximity of resources for processing the disposable cameras (film) -Participants were trained in photographic techniques to improve the picture quality
	Contingency plans for cameras	-One of the participants reported a broken camera. Research assistant had to replace the camera without delay	Established contingency plans in case participants' cameras are broken or lost before processing
	Distance, transport and time to reach study site	-The researcher underestimated the time needed to reach the research site and the type of transport needed	-In selecting study site, the following were considered: transport, distance and time needed to reach the site
3. Management: Establishing potential human and data management problems	Challenges of participants during Photovoice method and in filling WHOQOL-BREF questionnaire	-Some participants reported lack of transport to reach places where they wanted to take photos -Most participants needed privacy to answer some questions on the WHOQOL-BREF questionnaire	-Researchers continuously provided support to participants during the Photovoice method -Transport arrangements were made for some participants to access photo opportunities -Privacy and confidentiality in administering the WHOQOL-BREF questionnaire were ensured
	Number of photograph assignments and individual interviews	-Two photograph assignments and individual interviews were conducted and this ensured refinement of data	- Two photograph assignments and individual interviews were conducted to ensure that data was adequate
	Data storage	-Researcher stored the data in an encrypted file on the computer	-Data was stored in a secure, locked digital safe and on an encrypted file on computers -Data will be disposed of by shredding after 5 years
	Data dissemination	-Participants' and subjects' names were not used and faces were not shown	Names of participants were not used, and participants' faces on photographs were not shown

4.Scientific: Assessment of trustworthiness, response to Photovoice and WHOQOL-BREF questionnaire	Sample size	-6 participants were an ideal number for the Photovoice method and administering WHOQOL-BREF questionnaire	-Sample of 6-10 is ideal (Wang and Burris, 1997) -However, to test internal consistency of the WHOQOL-BREF questionnaire a sample >200 is ideal (WHOQOL Group, 1996) -Since this was an integration of two methods and since Photovoice preceded WHOQOL-BREF, the sample size for Photovoice was the same as that of WHOQOL-BREF -Eight participants per each study site were purposively selected with the help of Senior Rehabilitation Officer and utilising the participant characteristics as set out above
	Trustworthiness	-Lincoln and Guba model of trustworthiness was applied for Photovoice method. This ensured credibility, transferability, dependability, and confirmability	- Lincoln and Guba model of trustworthiness was applied when utilising the Photovoice method
	Identification of themes	Participants identified their own themes and sub-themes	CBR Matrix of the WHO was utilised as a framework to underpin identification of themes and sub-themes
	Duration of study	-This study lasted two weeks. However, WHOQOL-BREF questionnaire was administered to establish baseline on quality of life	- Duration of Photovoice method was determined by data saturation -The study lasted one month - For the current study, WHOQOL-BREF questionnaire was administered to establish baseline on quality of life -To measure change in quality of life as a result of CBR programme implementation, the WHOQOL-BREF can be administered over a period of 2 years
	Multiple study centres	-Only one site was utilised	-Photovoice and WHOQOL-BREF were implemented in conjunction in two study sites, comparing results
	Feasibility of combining the Photovoice method and WHOQOL-BREF questionnaire	-Utilising the same participants for both Photovoice and WHOQOL-BREF allowed for comparison and confirmation of Photovoice findings with WHOQOL-BREF	The same participants that were utilised in Photovoice method completed the WHO-BREF to allow comparison and confirmation of Photovoice findings with WHOQOL-BREF

Source: Adapted from Van Teijlingen et al(2001); Shumba and Moodley (2018a)

Objective

Utilising a combination of Photovoice and WHOQOL-BREF, the current study aimed to determine the convergence and divergence of Photovoice and WHOQOL-BREF in reviewing the experiences and quality of life, respectively, of persons with disabilities. Utilising qualitative content analysis of the participants' comments

about their CBR experiences in the Photovoice method and matching them with their respective quality of life results from the WHOQOL-BREF questionnaire, a convergence or divergence of their CBR experiences and quality of life was determined. Furthermore, the study aimed to propose a practice framework for CBR programme evaluation in Namibia.

METHOD

Study Design

The study utilised a qualitative phenomenological design. It describes and explores the integration of information of real-life experiences of persons with disabilities via the photographs taken by the participants, with an interview study that offers insight into their quality of life. This study took place in the context of a Community-Based Rehabilitation programme being implemented in selected rural communities of Namibia. The study methodology was guided by a set of study criteria developed by Van Teijlingen (2001) which was further adapted by the authors Shumba and Moodley (2018d) in their feasibility study.

Study Setting

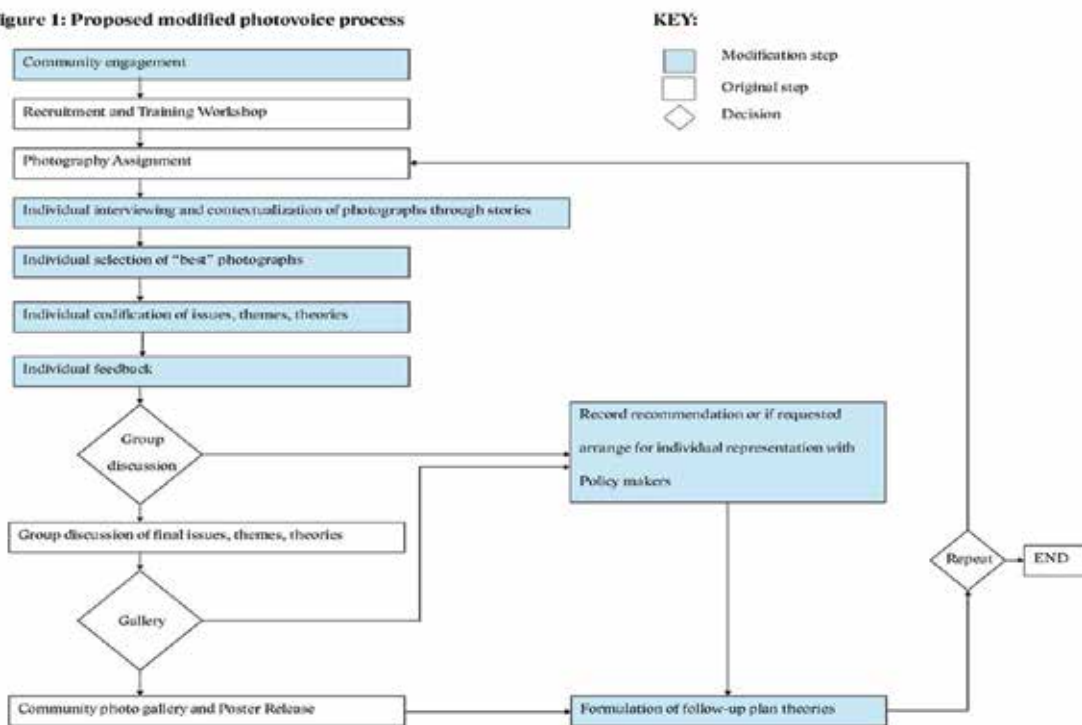
Two CBR study sites were selected, with diverse culture, terrain and disabilities. Stampriet is 350 km south of Windhoek and Otavi is about 440 km north of Windhoek. The two sites have different tribes with Stampriet having a predominately Nama and Damara speaking population, and Otavi with a predominately Otjiherero speaking population. Stampriet is administered under a village council and Otavi is administered under a town council.

Data Collection and Analysis

Data collection and analysis were conducted simultaneously. The primary data set used for analysis comprised photographs taken by the participants as well as the results from the WHOQOL-BREF questionnaire. The original WHOQOL-BREF English language and Afrikaans language versions were used, depending on the language each participant felt comfortable with. The Photovoice method preceded completion of the WHOQOL-BREF. The participants were involved in both phases of this study to allow for comparison and integration of information about lived experiences derived from the Photovoice method and their quality of life determined from the WHOQOL-BREF assessment.

Photovoice Method - Data was collected and analysed utilising the modified Photovoice method by Shumba and Moodley (2018c) which is illustrated in Figure 1. All individual interviews were transcribed verbatim, and the constant comparative approach (Patton, 2002) was utilised during the data analysis. Initially, there were individual interviews where participants were required to present their best 5 photographs and provide any explanation or details that they felt were very important. After each interview, a validation with each participant was conducted to confirm and increase credibility of the findings. Besides, the researcher and research assistant discussed the selected photographs with the participant, and compared these with their transcript to check if there was any information that required further in-depth probing.

Figure 1: Proposed modified photovoice process



After the Photovoice study a focus group workshop was held with all participants, to decide on themes and sub-themes for organising and clustering the photographs. Direct content analysis was employed where the WHO CBR Matrix (WHO, UNESCO, ILO & IDDC, 2010) was used as a framework to determine the themes and sub-themes. The WHO CBR Matrix was selected because it strongly emphasises the need for involvement of the community in CBR programming, and is resolutely underpinned by the United Nations Conventions on the Rights

of Persons with Disabilities (United Nations, 2006) which promotes the human rights model of disability.

At the beginning of the focus group workshop, the WHO CBR Matrix was shared with the participants by the researcher, and agreement was reached to utilise it for determining themes and sub-themes and organising the selected photographs. Each participant presented his or her photographs, and this was followed by a group discussion. Agreement on final themes was arrived at through group discussion. The researcher deemed the data saturated when no new statements were made regarding the meaning of the photographs and all the participants agreed on what was discussed. A detailed explanation of the whole Photovoice process is shown in Table 2.

Table 2: Procedure for Data Collection and Analysis

Step	Procedure	Duration
1. Community engagement	The research assistant organised a meeting with the local Councillor to discuss the purpose of the pilot Photovoice project in their community. Upon gaining approval from the Councillor, a date was set to meet with persons with disabilities who are beneficiaries of the CBR programme, CBR volunteers participating in CBR programme and caregivers/family members of persons with disabilities, to gain support and understanding of the Photovoice project.	½ Day
2. Recruitment and training	<p>For each CBR site, eight participants with diverse backgrounds were purposively selected for training. This training also served as a platform for participants to introduce themselves and get to know one another. The training discussed the following aspects: Photovoice process; group objectives; informed consent to participate and for photography subjects: how to use the camera; the basics on how to take photographs; general guidelines for photographs; special consideration/ ethical considerations when photographing human subjects. These training aspects are detailed below:</p> <ul style="list-style-type: none"> • Photovoice process Underlying issues around the use of the cameras in the community were discussed and emphasis was placed on focusing on the use of the camera and ethical concerns around taking photographs and the potential risks that may be faced as photographers. • Project objectives Participants were informed of the objectives of the pilot Photovoice study and that the study was for academic purposes only. It was important to develop framing questions to serve as guidelines for participants in identifying potential photographic subjects that would be meaningful for them and consistent with the objectives of the research. Instead of using the "SHOWeD" technique by Wang and Burris (1997) that was used in the preliminary assessment (Shumba & Moodley, 2017c), the team adopted the personal-questions approach by McIntyre (2003). The McIntyre approach empowers participants and assists them in codifying the photographs. 	

	<ul style="list-style-type: none"> • Informed consent to participate The researcher and research assistant guided participants through the informed consent form. Participants were informed that participation is voluntary and that they may discontinue at any time during the study. • Photography The researcher trained the participants on how to: use the camera; take photographs in relation to the subject matter, taking into account special consideration for human subjects. <p>Each participant was then issued with the following materials:</p> <ul style="list-style-type: none"> ❖ 1 disposable camera (27 exposure film) ❖ Subject consent forms for the photographed subjects to sign and confirm consent 	½ Day
3. Photography assignment	<p>This part of the project involved taking of photographs by the participants, collection of the cameras and signed consent forms, development of photographs, and reflection. Participants were given six days to take photographs and to return their cameras and the subject release forms to the research assistant, who then sent them to the researcher. About midway through the 6 days, the research assistant telephonically reminded the participants of their deadlines and offered encouragement and advice where necessary. Each study site had a participant group leader who would constantly update the research assistant on the progress. After six days, the researcher received the cameras and had the photographs processed (developed). Each participant's set of photographs were saved and coded on separate compact discs (CDs). This master set of CDs was retained in safe-keeping by the researcher. Processing of the photographs took a day.</p>	7 days
4. Individual interview, selection of "best" photographs, codification and feedback	<ul style="list-style-type: none"> • Individual Interviews During week two, the researcher and research assistant returned to the site with the processed photographs. Participants were requested to come to the Councillor's office at selected times for individual interviews. • Individual selection of "best" photographs Each participant was allocated time for individual selection of the "best" 5 photographs. These best photographs were supposed to describe their experiences regarding the CBR programme. • Individual codification of issues, themes, and stories The researcher requested each participant to club together photographs they had selected with similar meaning and identify a theme. Those belonging to one theme but of a sub-category were assigned to a sub-theme. McIntyre's(2003) personal questions were utilised: <ul style="list-style-type: none"> • Personal questions <ul style="list-style-type: none"> ▪ What is the meaning of these photographs to you? ▪ What is the relationship between the content of the photographs and how you perceive Community- Based Rehabilitation? ▪ Do you think the photographs are reflecting issues that are representative of the experiences of CBR programme by other community members? • Individual feedback During the feedback session, participants shared their challenges and achievements during the Photovoice process. At this point an atmosphere of trust allowed participants to express themselves freely. Participants also proposed other photographs that they could have taken but did not for various reasons. 	3 days

	<p>NB: On completion of individual feedback sessions, participants were invited to the local Councillor's office to share their selected photographs with the other participants in a group discussion. The aim of the group discussion was to select the final photographs that best represent a collective story of the CBR programme. However, participants were informed that the group discussion was voluntary, and they had the option not to share their stories in a larger group. All participants agreed to participate in the group discussion.</p> <p>Following these sessions, the researcher and research assistant transcribed verbatim all audio recordings, reflected on participants' selected photographs and debriefed on emerging themes.</p>	
<p>5. Group discussion of final issues, themes and stories</p>	<ul style="list-style-type: none"> ▪ Feedback on each others' photographs <p>On arrival at the Councillor's office, the group discussion participants were encouraged to circulate in the room, to view and reflect on all the photographs that were displayed on the walls, and to talk to other participants about their experience of taking and selecting photographs. At the same time, the researcher circulated among the participants to ask probing questions and take field notes.</p> • Presentation of the WHO CBR Matrix underpinning the identification of themes <p>At the beginning of the group workshop, the WHO CBR Matrix was presented to the participants as the framework underpinning the identification of themes for member check, accuracy and validation.</p> • Sharing of individual issues and presentation of themes <p>The researcher then used an LCD projector to display the selected photographs on a big board for each participant. All participants were allocated 20 minutes each to present their findings and were instructed to link specific pictures with the WHO CBR Matrix. The other participants were requested to refrain from asking questions during this process; they could however make a note of their clarifying questions and their own stories to share later in the final discussions.</p> 	<p>1 day</p>
	<ul style="list-style-type: none"> ▪ Group consensus of themes <p>This was done through full group discussion to ensure that the themes were represented and that all alternatives were explored. At this stage all participants could share their individual and collective experiences as they related to specific photographs, revising the underlying issues and themes. Consensus on the final themes and sub-themes was reached through discussion. The researcher deemed the data saturated when no new statements, regarding the meaning of the photographs, were made and all the participants reached an agreement on what was discussed.</p> <p>NB: The discussions and the workshop were closed with some discussion questions:</p> <ul style="list-style-type: none"> ❖ What did you learn about yourself, this group, and the community? ❖ What is the best way to present the findings? Do you prefer a photo gallery or a poster release? ❖ Can Photovoice be implemented on a larger scale in other regions? Suggest improvements to the Photovoice process. <p>At both CBR sites the participants opted for a poster release. The researcher then provided each participant with a CD with all photographs and hard copies of the photographs to distribute to their subjects as a token of appreciation.</p> <p>Participants were invited to share their experiences and photographs through a poster release. They were informed that this was voluntary, and they had the right to refuse. Most participants indicated the desire to create a poster for use during awareness-raising of CBR activities and commemoration of international and national disability days.</p> <p>The researcher and research assistant reflected on participants' selected photographs and debrief on final themes.</p> 	

6. Completion of WHOQOL questionnaire	<p>Upon completion of the group discussion, the participants were requested to complete the WHOQOL-BREF questionnaire by basing it on their life experiences during the past 2 years. The researcher administered the WHOQOL-BREF questionnaires that were already translated into Afrikaans and English. All participants in both sites were conversant with either English or Afrikaans. The researcher and research assistant supervised the completion of the English or Afrikaans WHOQOL-BREF questionnaire.</p> <p>The completed WHOQOL-BREF questionnaires were collected for manual calculation by the researcher, following the steps and formulas stipulated by the WHOQOL-BREF Instructions Manual (WHOQOL Group, 1996).</p>	
7. Poster release	The researcher developed the first draft of the poster and sent it to the participants for inputs through the research assistant. Inputs were given from both CBR sites and a final poster was released. Several copies were made for each CBR site.	14 days
8. Formulation of follow-up plan	The researcher asked each research assistant to meet the participants to develop an action plan to tackle some of the issues of concern identified.	Undefined

Source: Adapted from Wang and Burris (1997)

WHOQOL Questionnaire - After the Photovoice process was completed, the participants were requested to fill out the WHOQOL-BREF questionnaire on the basis of their life experiences during the past 2 years. The researcher administered the WHOQOL-BREF questionnaires that were already translated into Afrikaans and English. Participants chose the language they were conversant with - either English or Afrikaans. The researcher and research assistant supervised the completion of the selected questionnaire.

Data from the WHOQOL-BREF questionnaire was manually calculated following the guidelines and formulas stipulated in the Instruction Manual by converting the domain scores to transformed scores comparable with WHOQOL-100 (4 - 20 scale and 0 - 100 scale) as shown in Table 4 on page 11 of the WHOQOL-BREF Instructions Manual (WHOQOL Group, 1996).

Ethics Approval

Ethics approval was obtained from the Human Sciences Ethics Research Committee of the University of KwaZulu-Natal (Reference No: HSS/0646/015D) and the Ministry of Health and Social Services in Namibia approved to conduct this research (17/3/3).

RESULTS

The findings are presented under the following two headings:

- 1) Participants' characteristics, and
- 2) Degree of convergence and divergence between the Photovoice method and WHOQOL-BREF assessment.

Participants' Characteristics

The participants' demographics and reasons for drop out from this study are shown in Table 3. Of the initial 16 participants, 12 completed the study (7 in Otavi and 5 in Stampriet). Participants' ages ranged from 21-77 years and there were more females (n=10) than males (n=6) among them. The majority of selected participants had physical disabilities (n=12), visual impairments (n=3), and only one individual had a mental illness. Most participants were CBR volunteers participating in CBR programmes.

Table 3: Participants' Characteristics and Reasons for Drop Out

Participant Code	Study Area	Type of Disability	Age	Gender	Highest Education received	Completed study	Reason for Drop Out
O1	Otavi	Physical (lower limb paralysis)	77	Male	None	Yes	_____
O2	Otavi	Physical (lower limb amputation)	64	Male	Primary school	Yes	_____
O3	Otavi	Physical (lower limbs)	52	Female	Primary school	Yes	_____
O4	Otavi	Visual impairment (low vision)	58	Female	Secondary school	Yes	_____
O5	Otavi	Physical (lower limbs)	49	Female	Primary school	Yes	_____
O6	Otavi	Physical (upper limb and lower limb paralysis)	76	Male	Primary school	Yes	_____
O7	Otavi	Physical (lower limb amputation)	51	Male	Secondary school	Yes	_____
O8	Otavi	Visual impairment (blind)	41	Female	None	No	Took photos and lost interest before interviewing. Needed assistance in photography
S1	Stampriet	Physical (lower limb paralysis)	29	Male	None	Yes	_____
S2	Stampriet	Physical (cerebral palsy)	48	Male	None	Yes	_____
S3	Stampriet	Physical (cerebral palsy)	21	Female	Primary school	No	Took photos and lost interest in interviewing
S4	Stampriet	Physical (lower limbs paralysis)	44	Female	Secondary school	Yes	_____
S5	Stampriet	Physical (upper left limb amputation)	26	Female	Secondary school	Yes	_____
S6	Stampriet	Physical (blind)	24	Female	Secondary school	No	Was taken by family members to another town before interviewing
S7	Stampriet	Physical (left upper limb paralysis)	34	Female	Secondary school	Yes	_____
S8	Stampriet	Mental illness	47	Female	Primary school	No	Took a lot of photos on one item (obsessive tendency) and lost interest for interviewing

Convergence and Divergence of Photovoice Method and WHOQOL-BREF

Table 4 displays the convergence and divergence of results from the Photovoice study and the WHOQOL-BREF study. As depicted in Table 4, all participants in Otavi (n=7) were moderately satisfied with their overall quality of health. In contrast, all participants in Stampriet (n=5) were satisfied with their overall quality of health. Notably, most participants (n=8) in both study sites had low scores regarding their quality of relationships and social environment. It is noteworthy that Question 21, "How satisfied are you with your sex life?" did not elicit responses from almost all participants (n=11). This may be attributed to cultural norms where questions on sexual life are difficult to ask and the responses are restricted. The Photovoice method revealed negative experiences regarding environment (physical safety and security, home environment, financial resources, health and social care, access to information, recreation and leisure, physical environment, and transport). Most participants in both study sites reported that their quality of physical health and psychological well-being was fair.

Convergence was shown for example on S7 (Stampriet Participant 7) who had a high score on the overall quality of health (81%) and also expressed satisfaction with services provided at the local clinic. On the other hand, divergence was indicated with Stampriet Participant 4 who recorded a high score for psychological well-being (81%) but expressed negative experiences in her life. In general, there was a stronger convergence than divergence between the two methods.

Table 4: Combined Participants' WHOQOL-BREF and Photovoice Results

Participant Code	Domain 1: Physical health	Domain 2 Psychological	Domain 3: Social relationships	Domain 4: Environment	Overall Quality of Health	Overall Quality of Life	Photovoice Participants' responses	Convergence of Photovoice & WHOQOL-BREF	Divergence of Photovoice & WHOQOL-BREF
	0-100	0-100	0-100	0-100					
O1	44	19	44	25	3	3	<i>"The CBR programme has been working hard to secure wheelchairs for persons with disabilities. The CBR programme sourced a donation of wheelchairs from Ohorongo Cement Company for person with disabilities in this area. However the wheelchair is now too small to allow him to sit comfortably. As CBR volunteers we referred him for new measurements at the medical rehabilitation worker to get a new wheelchair"</i> (O1).	-Environment -Physical Health	-Psychological

O2	44	56	56	38	3	2	<i>"CBR volunteers referred him for physiotherapy. He has been receiving physiotherapy services and also received a wheelchair... as CBR volunteers we help him with some exercises at home...we feel we are helping him improve his health" (O2).</i>	-Psychological -Social relationships	-Overall quality of health
O3	38	56	44	50	3	3	<i>"This girl was born without one arm and has 2 kids but doesn't know the father of the kids. She went to school but dropped out early in primary education because of discrimination and has since refused to return. I (CBR volunteer) helped her to acquire a national I.D and disability grant. I am worried that she will continue being impregnated and abused by men and would like to refer her for adult education" (O3).</i>	-Psychological -Social relationships	
O4	44	81	44	63	2	3	<i>"I am taking care of this child with a disability and I also have a disability. He has athetoid cerebral palsy and I have challenges with balance in walking. I can't look for a job because this child needs my attention every minute. I always wish the government can also help persons like us within personal assistances so that we can also be able to seek employment and have time to socialise" (O4).</i>	-Overall quality of health	-Psychological -Environment
O5	81	56	44	44	3	2	<i>"This is a community toilet which used to be cleaned by the Council before the people were relocated to another location. In the new location there are no toilets and people come to this toilet. It is not clean and on top of that it is blocked and sewerage is everywhere. Even us persons with disabilities, including the visually impaired, use this toilet. We are very worried that this is a health hazard to this community" (O5).</i>	-Environment -Overall quality of life	-Physical health

O6	63	63	50	31	2	3	<i>"I (CBR volunteer) feel sorry and it hurt me that this man can't push his wheelchair and needs assistance every time to get out of his home especially when he is in need of medical treatment. The ambulances at the clinic don't pick up patients even those that are seriously ill. The clinic needs to consider the needs of person with disabilities, especially those who have mobility problems" (O6).</i>	-Environment -Overall quality of health	
O7	13	31	0	19	2	2	<i>"This is the town council, one of our public buildings, which is not accessible. There are a lot of stairs here and no ramp or lift. This is the same with the post office and Telecom... We (CBR volunteers) discussed this with the management of the different buildings and they appreciated the advice and promised to improve the accessibility" (O7).</i>	-Environment -Overall quality of life	-Social relationships
S1	56	81	56	31	3	3	<i>"I am grateful that the village Council built this toilet for me but unfortunately it is not accessible for me. I can't use it and when I feel like going to the toilet I go to the bush. Imagine the challenge I have in getting off the wheelchair in the bush and getting back. It's really painful and very risky for me. I have since reported this matter to the Councillor's office but there is no action. My sister who is also a CBR volunteer has supported me several times but still we haven't yet won" (S1).</i>	-Environment -Physical health	-Psychological
S2	50	44	50	56	4	3	<i>"I am using a wheelchair and I need assistance always to get in and out of my house as well as use my toilet. When I am left alone at home I can't use the toilet and go out of the house. The CBR programme has helped me to lobby with local business people to help with building a ramp at this door as well as renovating my toilet to make it accessible" (S2).</i>	-Psychological -Social relationships -Physical health	

S4	56	50	44	50	4	3	<i>"It is so sad that we (persons with a disability) have such a school which neither enrolls a child with a wheelchair nor a child who is deaf. It (the school) does not have ramps for wheelchairs or teachers for deaf children. These children are referred to Mariental or Windhoek where most times they don't have anyone to stay with... .."(S4).</i>	-Social relationships -Psychological -Environment	
S5	56	56	44	44	3	2	<i>"This is a primary school in my (CBR volunteer) area which is not accessible to persons with intellectual disabilities. It does not have a special class to cater for children with intellectual disabilities. All children with intellectual disabilities are referred to Mariental or Windhoek" (S5).</i>	-Environment	- Overall quality of life
S7	69	81	44	44	4	3	<i>"We (CBR volunteers) are happy with the services at this clinic. The nurses attend to you in a timely manner and the building is accessible in terms of toilets and the passages for persons with disabilities" (S7).</i>	-Psychological health -Physical health -Overall quality of health	-Environment

DISCUSSION

Notably, the ultimate goal of the CBR strategy is to improve the quality of life of persons with disabilities, yet most CBR evaluation frameworks fail to measure this critical aspect. The WHOQOL-BREF assessment offered an opportunity to measure the (baseline) quality of life of persons with disabilities who were involved in the Photovoice study.

Importantly, the scope of the current study only allowed for the measurement of the baseline quality of life and did not measure changes in quality of life due to the complexity of the process and limited time. Thus, future CBR research could consider longitudinally measuring changes in quality of life and CBR experiences, especially in new areas where CBR still needs to be implemented. However, some researchers have questioned whether there is value in repeatedly measuring some quality of life domains over time or just at baseline (Li, 2004). Domains such as psychological and social relationships may not change significantly over a short period of time due to diversity in type and age of persons with disabilities. Nevertheless, integrating the information about experiences of

persons with disabilities with their quality of life can help to get better knowledge and information about successes or failures of CBR. If more evidence can be provided about improved quality of life of persons with disabilities as a result of CBR interventions, this may give justification to intensify advocacy for CBR as well as soliciting for more funding for CBR programming.

The WHOQOL-BREF assessment offered an opportunity to measure the (baseline) quality of life of persons with disabilities who were involved in the Photovoice method. The overall quality of life of all participants in both study areas ranged from poor to neither poor nor good. Notably most participants (n=8) gave low scores in the social domain and environmental domain (WHOQOL Group, 1996). Findings from studies like this one can help CBR evaluators and planners to become aware of areas of interventions that require priority in CBR programming.

It is noteworthy that the low scores recorded in the social relationships domain were mainly due to most participants' reluctance to answer one of the items (Question 21) that explored their sexual satisfaction. This finding can be attributed to the larger number of female participants than males in the study. Sexual satisfaction tends to be determined by the type of disability, gender, and severity of the disability. Addlakha et al (2017) argued that sexual desire and satisfaction can be affected by a particular disability, governed by culture, socialisation, socio-economic class, and gender. Furthermore, women with disabilities often suffer lack of physical identity and mutual sexual experience, which accounts for their low sexual satisfaction. One of the issues that may be at stake in using a validated tool and certainly with a tool such as the WHOQOL-BREF - which uses scores - is the fact that if changes are being made (e.g., questions are changed, deleted or structurally not answered) one has to re-establish that the questionnaire is still reliable and valid. The fact that the question on sexuality was not answered by most participants influences the scores, although the instructions about computing scores make provision for incomplete assessments as long as the missing scores do not exceed 20%. However, this is not the case in the current study as one question only, in the social relationship domain, was not answered adequately. Given the importance of sexuality, a possible review of the WHO CBR Guidelines and national CBR policies should consider emphasising issues around sexual reproductive health rights.

The WHOQOL-BREF questionnaire was not user-friendly for some participants because of their low literacy skills as well as their non-English or Afrikaans-

speaking background. This resulted in some of them being unable to comprehend some of the WHOQOL-BREF assessment questions. In such cases the research team assisted in interpretation. This could potentially result in missed opportunities of correctly interpreting “big issues”, such as livelihood opportunities, that were important to participants. One of the key issues that some participants expressed concern about was opportunities for vocational training and income-generating projects.

The integration of Photovoice findings with the WHOQOL-BREF assessment revealed distinct social realities and milestones of the person’s quality of life. The Photovoice method allows persons with disabilities to reveal hidden but pertinent realities that are often missed by traditional data collection methods and are sometimes disregarded by family members, including social and sexual relationships. For example, the Photovoice study revealed teenage and unwanted pregnancy, particularly amongst persons with mental illness. However, the issue of sexuality was not adequately revealed by the WHOQOL-BREF assessment. Question 21 - “How satisfied are you with your sex life?” - did not elicit responses from almost all participants (n=11). This might be attributed to the social taboo associated with talking about sexuality in public. In this current study, HIV/AIDS and sexual reproduction have emerged as less prevalent issues for persons with disabilities. It thus could mean that the CBR programme in Namibia should consider placing more emphasis on HIV/AIDS and sexual reproductive health education. Photovoice as such could thus be an important complementary method to the more conventional methods such as interviews; something also observed by Jurowski and Paul-Ward (2007).

In some subject areas including physical health, the results of the Photovoice method matched the WHOQOL-BREF assessment as shown in Table 4. Current literature focusing on evaluation research (Grandisson et al., 2014; Madden et al., 2015) advocate for a mixed- method approach in CBR evaluative frameworks. Integrating Photovoice method and WHOQOL-BREF assessment is one such approach that helps researchers to understand and embrace the diversity in disability through interpreting life experiences and quality of life.

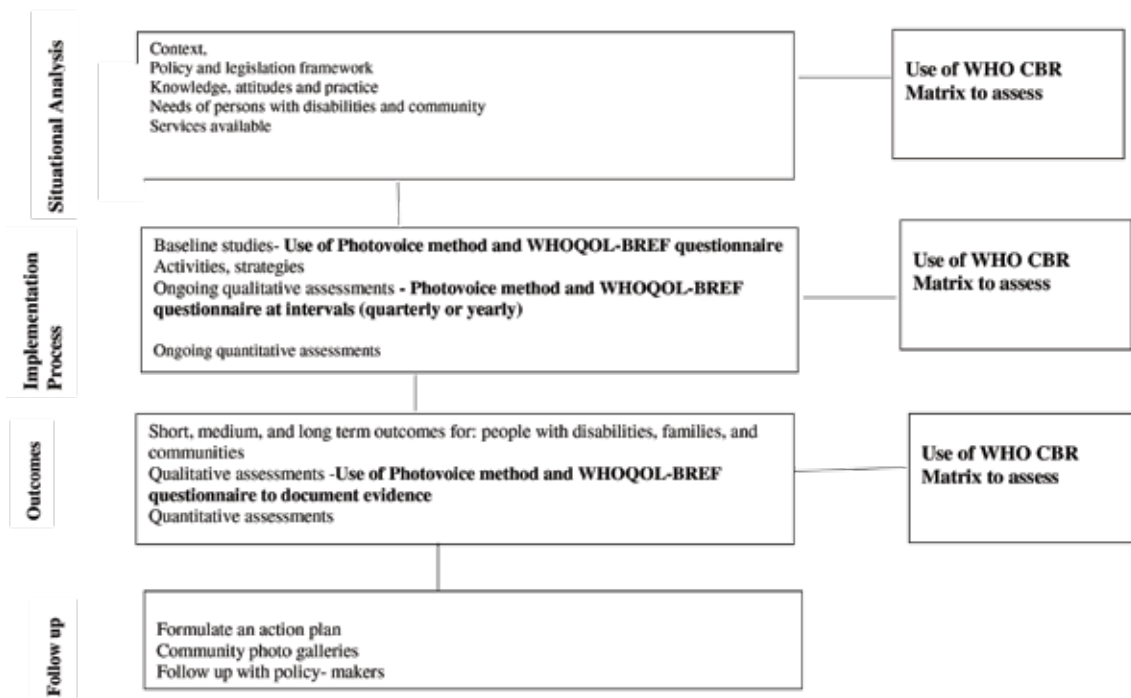
Implications

Based on the findings of this study, the following implications for practice are observed:

- Photovoice can help alleviate the challenges of research in areas with low literacy rates, which may be the case when doing research among persons with disabilities.
- Photovoice with the suggested modifications (see figure 1, Appendix II) allows persons with disabilities to reveal hidden but pertinent realities that are easily missed when using traditional data collection methods. Such realities are important for the person with a disability but may all too soon be disregarded by family members. This may, for instance, be the case when studying social and sexual relationships.
- The WHO CBR Matrix can be used as a framework underpinning CBR evaluation. Thomas (2011) and Grandisson et al (2014) proposed that the WHO CBR Matrix can be an important framework to be incorporated in CBR evaluations.
- The WHOQOL-BREF assessment tool can be utilised to generate information about quality of life of persons with disabilities but may be ineffective for persons with limited literacy levels unless support is provided from an interviewer who can explain questions that are not well-understood.
- When a review of the WHO CBR Guidelines takes place, more attention should be given to the realities of specific cultures and the issues around sexual reproductive health faced by persons with disabilities.

It is noteworthy that the WHO CBR Matrix and WHOQOL-BREF were integrated in analysing the results of this study to provide better insight into both the CBR experiences and quality of life of persons with disabilities in the two villages. To this end, this study proposes a practice framework (see Figure 2) for CBR programme evaluation in Namibia that integrates the WHO CBR Matrix, Photovoice method, WHOQOL-BREF and highlights from the other frameworks. Further research is required to validate the framework.

Figure 2: Proposed practice framework for CBR evaluation.



Limitations

The small sample size limits generalisability of the research findings. However, the results obtained are in-depth and possibly can be replicated. A large sample size is needed to confirm the findings of this study, especially with the WHOQOL-BREF assessment.

CONCLUSION

Integration of Photovoice with the WHOQOL-BREF needs to be more widely assessed as an additional tool for monitoring and evaluation of the CBR programme. The integration of Photovoice with the WHOQOL-BREF assessment can be conducted at initiation of CBR and as part of a longitudinal study to determine changes in lived experiences and quality of life of persons with disabilities. Further research is required to validate the proposed framework (Figure 2) for CBR programme evaluation in Namibia: a framework which integrates the WHO CBR Matrix, Photovoice method, WHOQOL-BREF and highlights from the other frameworks.

ACKNOWLEDGEMENT

The authors would like to thank the staff of the Ministry of Health and Social Services, office of the Vice President: Disability Affairs, Namibia, as well as CBR volunteers for making themselves available throughout this study. The authors would also like to thank Mr David Hughes, a disability consultant in Namibia, for his invaluable inputs.

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An Unclear Task?

Perspectives of Swedish Preschool and Special Needs Teachers on their Role in Assessing and Documenting Child Development

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ABSTRACT

Purpose: *This study explored how preschool and special needs teachers in Sweden perceive their own role and the role of each other in the preschools' documentation and assessment practices. It examines the possible consequences of this perception and of the actions based on it for children with special needs.*

Method: *The study took a qualitative approach. Individual semi-structured interviews were conducted with seven special needs teachers and seven preschool teachers from different schools and municipalities.*

Results: *The results show that the preschool and special needs teachers' roles regarding assessment and documentation, as described and specified in the curriculum, are contradictory and difficult. Assessing an individual child's knowledge development by observing and documenting the child group was regarded as problematic by both occupational groups, and further training in assessments was sought.*

Conclusion and Implications: *Clear differences were found between the way in which preschool teachers and special needs teachers performed observations and assessments and documented them. Preschool teachers mainly used participant observations at a group level, while special needs teachers were usually tasked with observing a particular child. Preschool teachers' reluctance to document the performance of individual children might result in children's special needs remaining hidden. It is important to find methods which endorse assessments that allow for and appreciate diversity, and that are not based on normative notions which often result in differentiating between children and*

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dividing them into different groups of learners based on their perceived level of knowledge.

Limitations: *From the interview results, it has sometimes been difficult to differentiate between the concepts of observation, documentation and assessment as they are often parts of a whole within the context of preschools. As the survey was of limited scope, the results cannot be generalised to all Swedish preschools, but the data obtained could provide important guidance for further work with inclusive preschools.*

Key words: *preschool, observations, documentation, assessments, children with special needs*

INTRODUCTION

During the last decade, preschools have to a higher degree been tasked with approaching learning as it is done in traditional school subjects. This tendency is apparent in the curriculum's design, the stated goals and pedagogical practice (Einarsdottir et al, 2015). In Swedish municipalities' educational management, the prioritised goals are those focusing on abilities in languages, mathematics, natural sciences and, of late, digital technology. Since the focus is now more often on the cognitive competence of the children, more voices are demanding that the educational efforts in preschools be documented and assessed.

Research within this field shows that the focus of documenting **child development** is frequently on the child as an individual and that learning as traditionally done in schools is deemed valuable (Löfdahl & Pérez Prieto, 2009; Lindberg, 2018; Nilfyr, 2018; Virtanen, 2018). The Swedish Schools Inspectorate (Skolinspektionen, 2011:10, 2012:7) shows in its reports that preschool teachers are unsure of how to document children's development and learning without assessing the children like teachers in formal school systems do. With the increasing focus on assessments, it is of interest to study those occupational groups that actually do the assessment and document the development of the child; in other words, study the role and tasks of **preschool teachers** and **special needs teachers**. The latter group is tasked with working with those children deemed to have difficulties in reaching the preschools' aspirational goals.

Earlier Research - Observation and Documentation

Observation

Observation as a documentation method became widely used in the 1950s and was then known as child observations. These observations derived from theories within developmental psychology; Gesell's maturation theory and Piaget's theory of cognitive development played prominent roles in the practise of objectively observing and measuring a child's development in comparison with the "normal" child (Tellgren, 2008). Today, observation is not considered an action in and of itself by most teachers; to them, it is an interaction between a teacher and child, an interaction where the teacher is a present and active co-agent. The notion of passiveness as a method of objectivity and of not influencing the observed child can still be found in preschools (Lenz Taguchi, 2013). It is not unheard of that observation templates measure a child's development according to established norms, criteria and levels regarding language development and mathematical thinking. These observation templates are however not compatible with the intentions behind the curriculum (Palmer, 2012).

Documentation

It is clear from the recommendations of the Swedish National Agency for Education (SKOLFS, 2017:6) that support efforts for children's development and learning are not prescribed by law. However, it is also clear that the documentation of these efforts must be continuously reviewed and assessed. Moreover, children's development should not be understood from established norms nor compared to that of other children but instead be understood from the social context that is the preschool. A child's need for extra support is always situational. This need is not a quality found in the child; it arises from what happens in the interactions between the child, the teachers and the preschool environment (SKOLFS, 2017:6).

Documentation can, according to Alvestad and Sheridan (2015), be understood from three perspectives. The first perspective is **limited documentation**, which focuses on the individual child's abilities and inabilities. The second perspective is **child-centred documentation**, which focuses on the activities in which the child takes part. The third perspective is **learning-oriented documentation**, which focuses on bringing to light the child's learning in relation to an object of learning.

An example of learning-oriented documentation, which can be used to develop pedagogical practice and to continue with didactic practice, is pedagogical documentation (Elfström, 2013). The term “pedagogical documentation” implies a working tool but also work material that is or has been the object of reflection (Bjervås, 2011). According to Bjervås (2011), creating pedagogical documentation requires not only observational skills but also an understanding of philosophical and theoretical perspectives as a basis for reflection and analyses. Despite the fact that teachers are becoming increasingly aware of this, there seem to be difficulties in finding a good organisation model for mapping changes in children’s knowledge (Alnervik, 2018; Kang & Walsh, 2018; de Sousa, 2019; Lee-Hammond & Bjervås, 2020).

Several studies show that preschool teachers are unsure of what documentation is required and how to create it (Lindgren Eneflo, 2014; Johansson, 2016; Hamilton & Hermansson, 2017). Recent research indicates that a performative approach dominates documentation as a whole and that the aim then is to present preschools in a positive light (Lindroth, 2018; Lindberg, 2018). Documentation is also becoming more digitalised (Virtanen, 2018); a possible consequence is the omission of the components of reflection and analysis from the documentation process, which instead then focuses on the act itself. Despite the fact that the intention, based on policy documents and research, is to conduct learning-oriented documentation, this development represents what Alvestad and Sheridan (2015) describe as child-centred documentation.

Assessment

Documentation and assessment can be seen as being dependent on one another. On the one hand, this can promote the uncovering of children’s changing abilities; on the other hand, documentation and assessments can also be misleading when children are assessed from a perspective of inability. In preschool documentation, several different forms of documentation, deriving from different theories, appear (Vallberg Roth, 2014). Many preschool teachers believe that an implicit component of observation and documentation is assessment to some degree. The more pronounced and formalised the documentation becomes, the more it resembles what would be considered an assessment. Assessment is regarded as an uncomfortable component that in its formalised and pronounced form prompts ambivalence and interferes with the preschool teachers’ pedagogical values (Karlsudd, 2021).

In preschools, there are elements of both summative and formative assessments, assessment forms that are primarily suited for the goals of compulsory schools and for measuring whether individuals possess required knowledge, not for the aspirational goals of preschools. The preschool's traditional working method has been inclusive and has created spaces for children to be children and develop in their own time without pressure and expectations (Sheridan & Pramling Samuelsson, 2016). This approach has led to preschool teachers opposing assessments to various degrees, as assessments can easily give rise to an approach that is less tolerant of diversity (Karlsudd, 2021). As special needs teachers have pointed out in previous studies, this poses the risk of children with special needs not being seen and therefore not receiving the support they need to develop as much as possible on their own terms (Renblad & Brodin, 2014).

The Role of the Preschool Teacher and the Special Needs Teacher within a Documentation and Assessment Practice

The curriculum for preschools includes specific guidelines that assign responsibility for systematic quality work (Skolverket, 2018). The preschool teacher's increased responsibilities in relation to other members of the team are also highlighted in the policy document; this can be understood as a consequence of the "New Public Management" trend that has influenced the way municipalities organise their services and resources (Wiesel & Modell, 2014). This means that preschool teachers are obligated to continuously and systematically document each child's development and learning and follow up by analysing the documentation. This task is supposed to allow for an evaluation of how the preschool provides opportunities for children to learn and develop in accordance with the goals of the curriculum and the intentions behind it. It is, therefore, not the children but the conditions for learning and the development over time within the pedagogical practice that is to be assessed (Sheridan et al, 2012). It is not uncommon for preschool teachers to express concern that the current documentation requires time that could have been spent with the children. Another concern is that documentation work can lead to an increased "schoolification" and that the preschool practice will therefore lose its unique character of care and learning in unity (Logan & Sumison, 2010; Grant et al, 2018). However, preschool teachers also view assessment as a profession-enhancing method, as an increased commitment to children's learning, and the mapping of this learning can be viewed as a sign of increased professionalism (Johansson, 2016). Another argument for documentation is that parents become more involved

in the preschool's activities (Löfgren, 2015; Paananen & Lipponen, 2018; Hostyn et al, 2020).

The System of Qualifications (SFS 2011:688, 2011) describes the knowledge and capabilities required of special needs teachers to finish their degrees. Regarding observation, documentation and assessment, it states that special needs teachers are expected to conduct pedagogical assessments, reviews and evaluations; they also need to be able to analyse difficulties at both group and individual levels. They should also be able to participate in the development of the pedagogical work and learning environment in order to meet each child's needs and act as qualified interlocutors for teachers, parents and other concerned parties. Assessments within special needs education are to be made on the basis of scientific research and ethical aspects (SFS 2011:688, 2011).

Objective

The objectives of the study were defined as follows:

- To establish how preschool and special needs teachers perceive their role and the role of each other in the preschool's documentation and assessment practices.
- To define the possible consequences and necessary actions based on the perception of preschool and special needs teachers towards preschool's documentation and assessment practices of children with special needs.

METHOD

Participants

The preschools where the preschool teachers and special needs teachers were employed or assigned were selected with socio-economic and geographical diversity specifically in mind. To achieve diversity regarding the informants' ages and experiences, the method of strategic selection was used. Seven preschool teachers and seven special needs teachers participated in this research. Half of the teachers within each profession had more than ten years of experience.

Data Collection and Analysis

The data gathering was conducted through semi-structured interviews. These were individual interviews in which the participants described their views on the

tasks of observation, documentation and assessment. The interviews concluded with questions on how the interviewees perceived the professional roles of both their own occupational group and the other group. To increase the validity of the question formulation (Patel & Davidson, 2019), the individual interview schedule was piloted; one with a preschool teacher and another with a special needs teacher. This resulted in minor adjustments being made.

Before the interviews, a letter guaranteeing the upholding of the principles of research ethics was sent to the participants (Vetenskapsrådet, 2017). This mainly meant informing the participants of the aim of the study and that participation was voluntary.

The interviews were recorded digitally, then transcribed and anonymised. Participants' anonymity was protected by allotting each one a unique identification number (1–14) without linking them to other information, such as gender or age. The seven preschool teachers were identified as 1–7 and the seven special needs teachers were identified as 8–14.

RESULTS

In the interviews, preschool teachers often spoke from a team perspective. This means that individual and personal ideas were often held back in favour of a more descriptive account of how the preschool teachers worked with the concepts of observation, documentation and assessment. The responses followed this pattern fairly often, as the preschool teachers viewed their role as being part of a collective.

The special needs teachers were more prone to give answers based on an individual perspective, as their role was fairly solitary. From the answers, it was sometimes difficult to differentiate between the concepts of observation, documentation and assessment, as these frequently were parts of a whole within the context of the preschools. In preschools, observation is now seldom seen as an act in and of itself, as it is part of the “multi-tool” known as systematic quality work.

Despite the similarities among the concepts, it has been possible to organise the results in the order in which the concepts were discussed: observation, documentation and assessment. The two occupational groups' perceptions of the other group's tasks and role are then presented: the interviews with the preschool teachers are followed by the interviews with the special needs teachers.

Observation

The **preschool teachers** explained that observations were mainly conducted through photographs and films. The objects of observation were mainly directed at processes taking place at a group level. The preschool teachers did not speak of observation as a concept in and of itself; instead, they interpreted it as a component of the pedagogical documentation. Regarding observations of individual children, the preschool teachers mentioned several observation tools and templates in which activities were observed on a group or individual level. Observations of individuals did occur but were not spoken of clearly and were expressed in indirect comments.

“If we are a bit concerned about a child, then first, you observe them a little in the background, by yourself or with colleagues” (Participant 2).

The **special needs teachers’** observations were based on their assignment. This could be about observing a group and/or an individual. Most assignments for special needs teachers were aimed at individuals, but they were also consulted for assignments at a group level.

“Most assignments we are given aim towards individuals, but we have reformulated our information so that it becomes clearer that you can also bring us in for group efforts” (Participant 11).

Before the observations were conducted, the special needs teachers met the preschool team so that they could convey how they viewed the situation/problem. Often, the special needs teachers had already reviewed the preschool teachers’ observation documentation before the visit. During the observations, the special needs teachers placed themselves somewhere neutral so as not to influence or disturb the children/child group.

“I observe it in the interaction between the child–adult, child–child, and try, as objectively as possible, to describe what happens here, how does the child interact, how does the child process instructions, how does the teacher give instructions. We can’t change a child; all we can change is how the teacher actually handles the interaction. They have to be the ones attempting to change” (Participant 9).

Special needs teachers with less experience mentioned that they would be helped by having some kind of observation schedule from which to work. Those who had more experience claimed to not need any specific observation templates. Knowledge and approaches seem to have been internalised.

"I note down observations continuously. I don't have a list of things I'm looking for, but because I've worked as a special needs teacher and preschool teacher for so long, I know instinctively what I want to see... and that is a lot. How does the child communicate, does the child understand what the others are saying, what the friend is saying, what the staff is saying, do they understand, do they follow the routines, how to interact with others, are they interested or uninterested in other children and do they continue with an activity for a long time or just a short while? That's what I think is the main essence of my observation" (Participant 8).

Special needs teachers claimed that they used a relational perspective when they discussed interaction, communication, environment, concentration and attention in connection to the teachers, the group and the learning environment.

The differences between the two occupational groups were apparent from the fact that the preschool teachers mainly used participant observations at a group level, while the special needs teachers were usually tasked with observing a particular child.

Documentation

The **preschool teachers** stated that they documented the children's learning at a group level and that this was usually included in the systematic quality work done at the preschools to develop the practice. The documentation regarded what children did and said and was conducted through, for example, photos, videos and notes, all collected digitally under easily understood headings connected to the goals in the curriculum. In order to quickly inform the legal guardians about the preschool's activities, it was also common to document the activities online, for instance by using programmes like Instagram. Digitalised documentation seemed to have caught on in practice.

"Earlier, we sent out a weekly newsletter by email, and then there were very few who read it, and then we think that it is easier if they are sitting with their phones, using Instagram anyway, that they ask the children, 'well, what did you do?' and somehow have a conversation with the children" (Participant 4).

According to the interviewees, there were clear structures and examples of how to document at a group level, where the preschool teachers discussed children's changing abilities. However, there was no clear structure for documenting an individual child's development and learning which, according to the curriculum

(Skolverket, 2018), the preschool teachers were supposed to systematically and continuously document and analyse. Consequently, they expressed uncertainty regarding this assignment.

“And the individual child, we don’t document them specifically, well, we do have the material that we base our development talks on that can be a kind of documentation as we do save that, and then you look back a little when it’s time to write again and then that becomes a kind of documentation of the child’s development, I think” (Participant 6).

Some preschool teachers thought that introducing the concept of teaching into the curriculum might result in increased documentation and greater responsibility for them in the long term. They wished that the concept of teaching would be adopted by preschools and incorporated to include children’s play and learning; this was evident in some answers. According to the preschool teachers, the ability goals would be given more weight than the value goals, and therefore they were concerned that the goals to which the preschools aspire would turn into goals that have to be met.

“I think that the schoolification will continue as the preschool class is now mandatory, and that is one step closer to us, so I definitely think that will spread to our level as well, and that they will expect children to know certain things about mathematics and Swedish language” (Participant 5).

Another factor that was raised was how individual documentation was becoming more digitalised through different types of “documentation platforms”. Much uncertainty was expressed regarding how the documentation of individual children had to take place. It was evident that the preschool teachers were vague on the topic. The curriculum (Skolverket, 2018) recommends that each child’s development and learning be continuously and systematically followed, documented and analysed, but the preschool teachers felt that there were no instructions as to how this was to be done.

The **special needs teachers** described how they documented their assessments and observations in order to analyse and reflect on the observed situation before providing feedback and guidance to the team. Several special needs teachers made it explicitly clear that this documentation was shared neither with other personnel nor the parents.

“It’s up to the teachers to note down what they feel they want to bring with them or they want to keep. The documentation I keep, I keep to myself and I never share it” (Participant13).

Some special needs teachers pointed out that there was no legal obligation to document a child in need of extra support from the preschool, in the form of action plans and action programmes.

“In our catchment area, we have decided together with the principal that we won’t make action plans here and there; instead we only make them if in very, very particular situations” (Participant 10).

There were no recommendations regarding how the documentation of children with special needs was to be arranged, nor how other professionals were to cooperate. One special needs teacher revealed as much.

“One problem that we have discovered here... if I’m assigned a child, and then that child is, for example, hearing-impaired, then there comes another special needs teacher who specialises in hearing impairments. Then, she makes her own notes, and I make mine, and they are always not similar. I feel like there should be a record system that actually takes the little child’s integrity into account” (Participant 9).

The special needs teachers indicated that they did not use systematic documentation like the preschool teachers did. They made it clear that they kept their documentation to themselves. If the team asks them for documentation, an “adapted” and summarised version might be given to them.

The mapping done by the team, with or without the help of a special needs teacher, was a form of documentation. Suggestions for extra measures, drawn up together and with the special needs teacher’s observations given a prominent role, formed the basis for the possible establishment of an action plan. The action plans aimed at both groups and individuals, and measures were suggested to be taken at a group level.

“I always make sure when reviewing to look at the group... because then I say that what is good for all children is also good for [child’s name]. We have discussed if we should set up goals for the preschool or for the child... That’s the crucial problem” (Participant 11).

Assessment

The **preschool teachers** claimed that it was the practice of preschool assessment of the development of the child that was being assessed through the systematic quality work. A majority of the preschool teachers maintained that it was the personnel's approach that was assessed to a greater extent than the individual child's performance. Assessment is a charged word that gives rise to many thoughts.

"There are many reprimands that you shouldn't assess, but you still have to make some form of assessment because otherwise you will never be able to see the individual child, because we are all different, so you feel a bit conflicted" (Participant 7).

"Yeah, it's easy to think of assessment as something negative, but it doesn't have to be, it can be a positive thing that can help us develop our practice. I have to assess myself in order to develop" (Participant 1).

The respondents shed light on, and discussed the concept of, assessment at their preschools but their views differed on whether assessments should be done. None of the preschool teachers mentioned that assessments were done of the individual child, despite the fact that they said that it should be legitimate to do so as they need to be able to see each child's needs for the child to develop as much as possible. Many avoided taking a stance on the concept and played it safe, but it was accepted to some degree that assessments were necessary.

"Assessments of the child do happen despite being really taboo, but in development talks you can interpret it in many different ways what you write, and that often differs from what you say later; that can probably definitely be interpreted as an assessment of the child. Also, it depends on what values you ascribe to the word, I think" (Participant7).

"Of course, it's our task to see the individual child. We have to help them if they need support, and if you can't make an assessment, then how are you to see that? You have to see the children to help them" (Participant 6).

"In my opinion, a child should receive as much help as possible. I have discussed this with other colleagues; it turns into a real dispute. It's a hot potato within preschools... You're not supposed to single out a child, and one way is to look the other way –'well, we're all different' " (Participant 3).

The respondents did not use the terms formative and summative assessment. There was, however, a clear distinction between the two concepts in the answers, as the systematic quality work, the learning process on a group level and assessments of the personnel's perceptions could be considered formative assessment. Summative assessment could be seen in the discussion of the individual child in relation to the goals set and in the fears that preschools were becoming more like compulsory schools.

All the **special needs teachers**, except one, claimed that they made assessments based on the mappings and observations that they had received from the team or that they themselves had made. They chose their words carefully when discussing the concept of assessment. The more experienced special needs teachers talked of the child's expected development; age-appropriate behaviour and typical development was something they noticed but did not pay too much attention to. Their focus was instead on guiding the teachers in adapting the learning environment and conveying a clarifying pedagogy. If there were no changes in the child's development, despite pedagogical efforts, the special needs teachers might deem that the case needed to be assessed by a psychologist. This was not entirely unusual, according to them.

The special needs teachers described assessment from a relational perspective. They talked of assessing the quality of the education, how the personnel interacted with the child, and not from a perspective of inabilities found in the child. Several special needs teachers mentioned that they made intuitive assessments based on theories within developmental psychology, but that this was not documented in action plans as the measures then risked being aimed at an individual (cf. Palla, 2018).

"It might sound a bit strange, but I make an internal assessment, and then I assess the child's ability to communicate. Can the child understand what is happening? Can the child make themselves understood?... Introverted or expressive?... I assess a little there" (Participant 8).

The fact that they did note *"the typical development"*, as a special needs teacher phrased it, was legitimised by a perceived responsibility to be the one to forward the case for further assessment by, for example, a psychologist. The special needs teachers emphasised that the concepts of assessment and teaching, and the meaning of these, were open to interpretation and should be discussed in every preschool.

What Preschool Teachers and Special Needs Teachers Expect from One Another

The **preschool teachers** said that they expected the special needs teachers to support the team through in-service training in diagnoses and disabilities and through concrete solutions, ideas and tools for moving forward when a problem arises. The preschool teachers also expected the special needs teachers to have more expertise in working with children with special needs and seeing what needed to be done.

“My expectations are that the special needs teacher should contribute with something that is outside our area of expertise, that we have tried to support and help the child as much as we can and know how to, but when we no longer know what to do, that she knows more than that and that she has a tool or a way of reaching the child, a tool to go forward with” (Participant 7).

The **special needs teachers** said that they expected the preschool teachers to be prepared before the first meeting and to be able to express what help they needed and what measures had been taken. They also expected the preschool teachers to be able to see their own roles, what they do and what they do not do, instead of blaming the child. They claimed that the preschool teachers themselves had the resources and a good understanding of the curriculum, enabling them to carry out their tasks. The special needs teachers also expected the preschool teachers to be curious and open to finding and trying out new solutions, and open to receiving further training in areas needed to support the child group. The special needs teachers claimed that it was up to the preschool teachers to adopt and continue with the suggestions and recommendations given.

“I expect the personnel to be curious and willing to learn. That’s how we merge your knowledge and experiences with my knowledge and experiences, and then we lift each other, and then we lift the child” (Participant 11).

DISCUSSION

The documentation task given by the curriculum can be perceived as contradictory and hard to carry out. Preschool teachers are expected to document each child’s development without making assessments, while the preschool’s practice is to be assessed in relation to the aspirational goals regarding the individual child (Skolverket, 2018). This setup creates a conflict between documentation and assessment. It is a delicate task, on the verge of impossible, to assess an individual child’s knowledge development without

observing and documenting it and without implicitly or explicitly conveying an individual assessment through this.

Graded knowledge assessments and assessments based on personality psychology were not supported by the preschool teachers, special needs teachers or the curriculum (cf. Vallberg Roth, 2014). That those active within the preschool practices dissociated themselves from individual assessments was most likely due to a non-normative perspective dominating within the preschool practices. Another reason for not highlighting the individual child's abilities and development could very often be that the systematic quality work was so clearly aimed at the child group. The tradition of preschools being safe spaces, free from the need to perform and assess, combined with the significance of play for the children's development and with the socio-cultural framework of the curriculum, most likely contributed to a certain degree of resistance to documentation in general and assessment in particular.

Despite the fact that the concept of assessment carries many connotations within preschools, the study results show that preschool teachers sought legitimacy by being allowed to assess the child's changing abilities through formative assessment. The interviews with the preschool teachers illustrate that the reluctance to assess was giving way (cf. Virtanen, 2018). This was partly due to the concepts of teaching and assessment having been discussed at the preschools.

Intentions, Ambivalence and Uncertainty

The preschool teachers' intentions seem to be to conduct a learning-oriented documentation that highlights children's learning in relation to an object of learning (cf. Alvestad & Sheridan, 2015). Despite these intentions, preschool teachers frequently ended up conducting child-centred documentation in which the activities that the children participated in, "the doing," were documented to show children and parents what was happening within the practice. It can be difficult to highlight changing abilities in the documentation. This is especially difficult when preschool teachers are afraid of being perceived as advocates for a perspective based on inabilities and the individual, often known as a categorical or compensatory approach (Karlsudd, 2017).

Based on statements from those participating in the documentation, the special needs teacher was the one mainly responsible for documenting the individual child. The observations that form the basis for the documentation are mostly

conducted as non-participant observations. Special needs teachers felt, to some degree, responsible for documentations which included mapping in some form and making an action plan, but they were unsure of how and to what extent they were supposed to document (cf. Palla, 2016). They also found it difficult to know what to do with that documentation. The special needs teachers were reluctant to produce any written material, and if they did, it was treated as personal notes which were not necessary to save for record-keeping.

Division of Responsibility

When the curriculum (Skolverket, 2018) states that **the preschool** is to observe children who for various reasons need extra guidance, incentives and support, the division of responsibility between preschool teachers and special needs teachers is unclear. Neither of the two professions are guarantors of the measures founded on documentation being conducted for the sake of the individual child. Only when the curriculum refers to the preschool class is it apparent that it is the preschool teacher who is responsible for observing children in need of extra support for development. In most cases an achievable division of responsibility has been established, but without more explicit regulations of this division the equality of the practices is jeopardised. In the worst-case scenario, this might lead to a child attending preschool for five years before one of the professionals, through a structured and formal approach, observes that the child needs extra support.

The relational perspective, which characterises the special needs teachers' discussions of children with special needs, seems to be reflected by the preschool teachers, who adopt the suggestions for changes in the learning environment and the approaches recommended by the special needs teachers. Special needs teachers are expected to possess a greater understanding of the possibilities for supporting the individual child, and that understanding is conveyed to the preschool teachers, who transform it into action.

Implications for Special Needs Education

To achieve equality in preschools and to be able to take early measures, children in need of extra support need to be given the right to have their needs noticed and documented. Preschool teachers' reluctance to document the individual child might result in children's special needs remaining hidden, as it is only the group's development and learning that is depicted. It is therefore important that

there is a method for assessment that does not include judgements. Assessment in its current form is usually based on normative notions which, within the education system, often result in differentiation.

It is evident that the preschool teachers sought further training on “how” and “what” to document when it came to the individual child. One step towards improving the preschool teachers’ expertise is to work towards a better understanding of inclusive special needs education. This would make it easier to identify and meet children’s special needs at an earlier stage. If the preschool teachers feel that they lack the knowledge required to document the individual child and assign responsibility for this to the special needs teachers, there is a risk that the latter will be seen as the ultimate authority. A better solution is that the special needs teachers do preventive work, together with the team, with child groups at a few preschools.

Limitations

As the survey was of limited scope, the results of this study cannot be generalised to all Swedish preschools, but the data obtained is expected to provide important guidance for further studies and evaluations.

CONCLUSION

The present study shows that preschool teachers have difficulties in finding a balance between group and individual-oriented observations and documentation. In this occupational group the dilemma is noticeable. On the one hand, there is a concern that the documentation practice will be developed into individual assessments that reduce the scope of children’s differences, while on the other hand is a concern about the risk of underestimating children’s need for special support. The special educators have a clearer and more direct responsibility for the individual assessments, although they themselves would like to observe and develop the activities for the whole group.

A proposal for further research is that the two professional groups together, in an action research project, might develop and test documentation for more inclusive assessments and work for activities that lead to the individual being put at the centre with the support of group-oriented initiatives.

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Cross-Cultural Adaptation and Validation of the Fatigue Severity Scale among Kannada-speaking Individuals with Neurological Disorders: A Cross-Sectional Study in South India

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ABSTRACT

Purpose: *The Fatigue Severity Scale (FSS) has been translated and validated in many languages across the world. Since it is a self-reported scale, it is necessary for clients to understand the components in order to quantify them. However, to date, the version in Kannada, the language spoken locally in the state of Karnataka in South India, has not been validated. This study aimed to perform cross-cultural adaptation and determine concurrent validity and test-retest reliability of the Kannada version FSS among Kannada-speaking individuals with neurological disorders.*

Method: *A cross-sectional study was conducted in the neuro-rehabilitation unit of a tertiary care hospital in southern Karnataka. Cultural adaptation of the scale was targeted at the Kannada-speaking population. It was pilot tested among 30 individuals with neurological conditions. The adapted scale was then evaluated for concurrent validity along with the Visual Analogue Fatigue Scale, by correlating the scores of fatigue assessed by both the scales among 83 participants. Reassessment of fatigue was done on all the participants the following day, to determine the test-retest reliability of the Kannada-version FSS scale among individuals with neurological disorders.*

Results: *The Kannada version of the Fatigue Severity Scale showed an excellent correlation with Visual Analogue Fatigue Scale scores ($r = 0.71$, $p < 0.001$) and good intra class correlation coefficient ($\alpha = 0.92$) with reassessment scores."*

The fatigue scores showed no significant difference ($F = 0.9$, $p = 0.5$) when compared across various neurological conditions."

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Conclusion and Implications: *The culturally-adapted Kannada version of the Fatigue Severity Scale has proved to be a valid and reliable tool to assess severity of fatigue among Kannada-speaking individuals with neurological disorders. It could therefore be used routinely as an efficient tool for the effective assessment and management of fatigue in clients with all types of neurological conditions.*

Key words: *fatigue, nervous system diseases, reproducibility of results*

INTRODUCTION

Fatigue is a multifaceted concept and a commonly used term associated with several interpretations, disciplines and meanings. Clinically, fatigue is described as an “overwhelming sense of tiredness at rest, exhaustion with activity, lack of energy during daily tasks or lack of endurance or vigour” (Kalkman, Zwarts, Schillings, van Engelen & Bleijenberg, 2008). It is challenging to describe fatigue because of its subjective nature and the inability to differentiate between muscle weakness, normal tiredness, daytime sleepiness, cognitive fatigability and depression, yet it is a prominent symptom in multiple medical and neurologic disorders (Al-Sobayel et al., 2016). Around 5% - 45% of community and primary care studies report fatigue as a major symptom which persists for up to six months in 2% -11% of the population (Kluger, Krupp & Enoka, 2013).

Fatigue is a dominant symptom in many neurological conditions including Stroke, Myasthenia gravis, Multiple Sclerosis, Traumatic Brain Injury, and Parkinson’s disease which is independent of sleep deprivation, mood disorders and medications (Kluger et al., 2013). However, because of its uncertain nature and the difficulty in describing it as a single entity, assessing it is a problem (Al-Sobayel et al., 2016).

Assessment of fatigue subjectively can be carried out through various methods including client-reported questionnaires, maintaining a diary or through interviews. Objective measurement mainly focuses on physiological process or performance (Laranjeira, 2012). Client-reported questionnaires have been proven effective in determining fatigue (Sharma & Sheth, 2019). Various questionnaires like Fatigue Severity Scale (FSS), Visual Analogue Fatigue Scale (VAFS), and Multidimensional Fatigue Inventory are developed and used to measure fatigue symptoms (Hewlett, Dures & Almeida, 2011). The most commonly recommended fatigue-specific scale is the FSS (Friedman et al., 2010). Published in 1989, it covered physical, social and cognitive aspects of fatigue in clients with multiple sclerosis and systemic lupus erythematosus (Krupp, LaRocca, Muir-Nash &

Steinberg, 1989).

The psychometric properties of FSS showed good validity, reliability and high internal consistency in various disease populations (Whitehead, 2009). This scale is widely used in clinical practice and research, and has been translated into a number of languages including Arabic (Al-Sobayel et al., 2016), Brazilian (Valderramas, Feres & Melo, 2012), Dutch (Rietberg, Van Wegen & Kwakkel, 2010), and Finnish (Rosti-Otajärvi, Hämäläinen, Wiksten, Hakkarainen & Ruutiainen, 2017) to name a few. In India, linguistic translation and adapted versions are available in Hindi/ Punjabi (Paul et al., 2016) and Gujarati (Sharma & Sheth, 2019). Though a Kannada version of FSS is available (translated by Dr Lauren Krupp along with MAPI Institute, which was obtained through personal communication dated 12th December, 2018), it has not been tested on people who speak the Kannada language. Assessment of fatigue is directed towards the specific client group, and cultural factors may have a significant influence on the assessment. Hence, translated versions need to be validated before they can be used for assessment in the specific population (Rosti-Otajärvi et al., 2017). To date, the Kannada version FSS has not been culturally adapted or validated among the local Kannada-speaking population.

Objective

The aim of this study was to cross-culturally adapt and pilot test the FSS among Kannada-speaking individuals with neurological disorders, and further evaluate its concurrent validity and test-retest reliability.

METHOD

Study Design

The author of the original FSS was contacted and permission to use, culturally adapt and validate the Kannada version of the FSS was obtained.

A cross-sectional study was then conducted in two phases.

Study Sample

All the participants were recruited from the neuro-rehabilitation unit of a tertiary care hospital in southern Karnataka.

Clients admitted in the hospital with neurological conditions and complaining of fatigue were included if they were:

- Older than 18years,
- Cognitively sound, and
- Able to read Kannada.

Excluded were those:

- With communication disorders,
- Undergoing treatment with immunomodulatory drugs,
- With co-existing disorders of other systems influencing fatigue, and
- Unable to understand simple instructions.

Tools

Fatigue Severity Scale (FSS) – This is a unidimensional 9-item client-reported scale which measures the physical, social and cognitive aspects of fatigue. The questions are mainly associated with how fatigue interferes with certain activities, and rates the severity on a 7-point Likert scale where ‘1’ indicates ‘strongly disagree’ and ‘7’ indicates ‘strongly agree’. The overall score will be the average of the scores of the individual items. The total score of 4 or >4 will indicate fatigue; the higher the score, the greater the fatigue severity (Learmonth et al., 2013).

Study participants were asked to rate their level of fatigue during the past week.

Visual Analogue Fatigue Scale (VAFS) - This is a 10cm horizontal line with descriptions “No fatigue” and “Very severe fatigue” written at either end. Participants are asked to mark the place on the line that they think defines their fatigue level best. The distance is then measured from the “No fatigue” end up to the client’s mark. Scores range from ‘0’ to ‘100’mm; the higher the score, the greater the levels of fatigue (Tseng, Gajewski & Kluding, 2010). Study participants were asked to mark the place on the line which they thought best indicated their current level of fatigue.

Data Collection

Phase 1: Cross cultural adaptation and pilot testing of the scale

Five individuals with different educational backgrounds, fluent in Kannada and with good understanding of the language, were selected for the process of cultural validation. They were asked to read the items and scoring criteria of the previously translated Kannada version of FSS. All the individuals were asked to comment on the clarity, comprehensiveness and simplicity of the scale items and scoring criteria. Based on their comments, the semantic, idiomatic, experiential and conceptual equivalence of the Kannada version of FSS was assessed and the required modifications were made.

The culturally-adapted Kannada version FSS was administered to 30 participants (Beaton, Bombardier, Guillemin & Ferraz, 2000) with different neurological conditions. The items and method of scoring were explained in Kannada. Participants were asked to mark the amount of interference with their activities that fatigue caused, which would indicate their level of fatigue. Adequate time was provided for all of them to complete the scale. The filled-out forms were collected and stored. During the pilot testing, frequency of responses, participants' ability to understand the questions and time taken to complete the scale were noted to evaluate the administrative burden of the scale.

Data Analysis

The data was analysed and the values obtained were used to estimate the sample size for the next phase of the study. The sample size calculated was 35 for concurrent validity and 83 for the test-retest reliability; however highest sample size of 83 was used for both the phases. The formulae used to calculate sample size were as follows:

Concurrent validity: $n = [Z\alpha + Z\beta]^2 + 3 / [C(r)]^2 = 35$ where, $c(r) = 1/2 \log_e(1+r / 1-r)$, $Z\alpha = 1.96$, $Z\beta = 0.84$ and $r = 0.5$.

Test-retest reliability: $n = Z\alpha^2 \sum^2 / d^2 = 83$, where, $Z\alpha = 1.96$, $\sum = 0.7$ and d (precision) = 15 %.

Phase 2a: Concurrent validity

Selection of participants for these phases of the study was done as mentioned above. Detailed information regarding the study was provided to all the

selected participants, after which their written informed consent was obtained. Demographic details of all the included participants were collected and they were then assessed for fatigue using Kannada version FSS and VAFS.

The participants were instructed to read the items of the Kannada version FSS and score according to the level of their fatigue, as explained earlier. To determine concurrent validity, they were all asked to grade their fatigue level using VAFS. FSS and VAFS were used alternately on participants to eliminate the sequence bias. The fatigue scores from both the scales were entered and used to analyse the concurrent validity of the Kannada version FSS against the VAFS.

Phase 2b: Test-retest reliability

All the participants with neurological disorders, who were included for concurrent validity testing, were included for the test-retest reliability as well. The participants were visited again after one day and the procedure was repeated to assess the severity of fatigue using Kannada version FSS. Since fatigue as a symptom is highly variable with time and can be altered with prevailing experience, intervention or mood, this time interval was chosen (Laranjeira, 2012; Chang, Gillespie & Shaverdian, 2019). The items within the scale were rearranged during the second assessment to eliminate the learning effect and sequence bias. Even though the clients tried to recollect the order of the items during the first assessment, they would not be able to score in a similar way due to changes in the presented order during the second assessment. This will possibly eliminate learning effect and sequence bias (Ngo, Stupar, Côté, Boyle & Shearer, 2010). The time of assessment was kept the same for both the assessments on consecutive days. Data obtained from both the sessions were entered and used to analyse the test retest reliability of the Kannada version FSS.

Data Analysis

SPSS version 16 was used for data analysis. Descriptive statistics were used to describe all the demographic variables. Spearman's Rank Correlation Coefficient was used to determine the concurrent validity of Kannada version FSS, and Intra-class Correlation Coefficient (ICC) was used to determine the scale's test-retest reliability. Mann-Whitney U test and One-way ANOVA were used to compare the FSS scores between gender, sleep time, duration, age, and across different neurological conditions. Level of significance was set at $p < 0.05$ for all the analyses.

Ethics Approval

Approval was sought from the Institutional Ethics Committee, Kasturba Hospital, Manipal, Karnataka (IEC No: 103/ 2019), and the trial was registered under Clinical Trial Registry of India (CTRI/2019/04/018730) prior to recruitment of the first participant for the study.

RESULTS

Cross-Cultural Adaptation and Pilot Testing

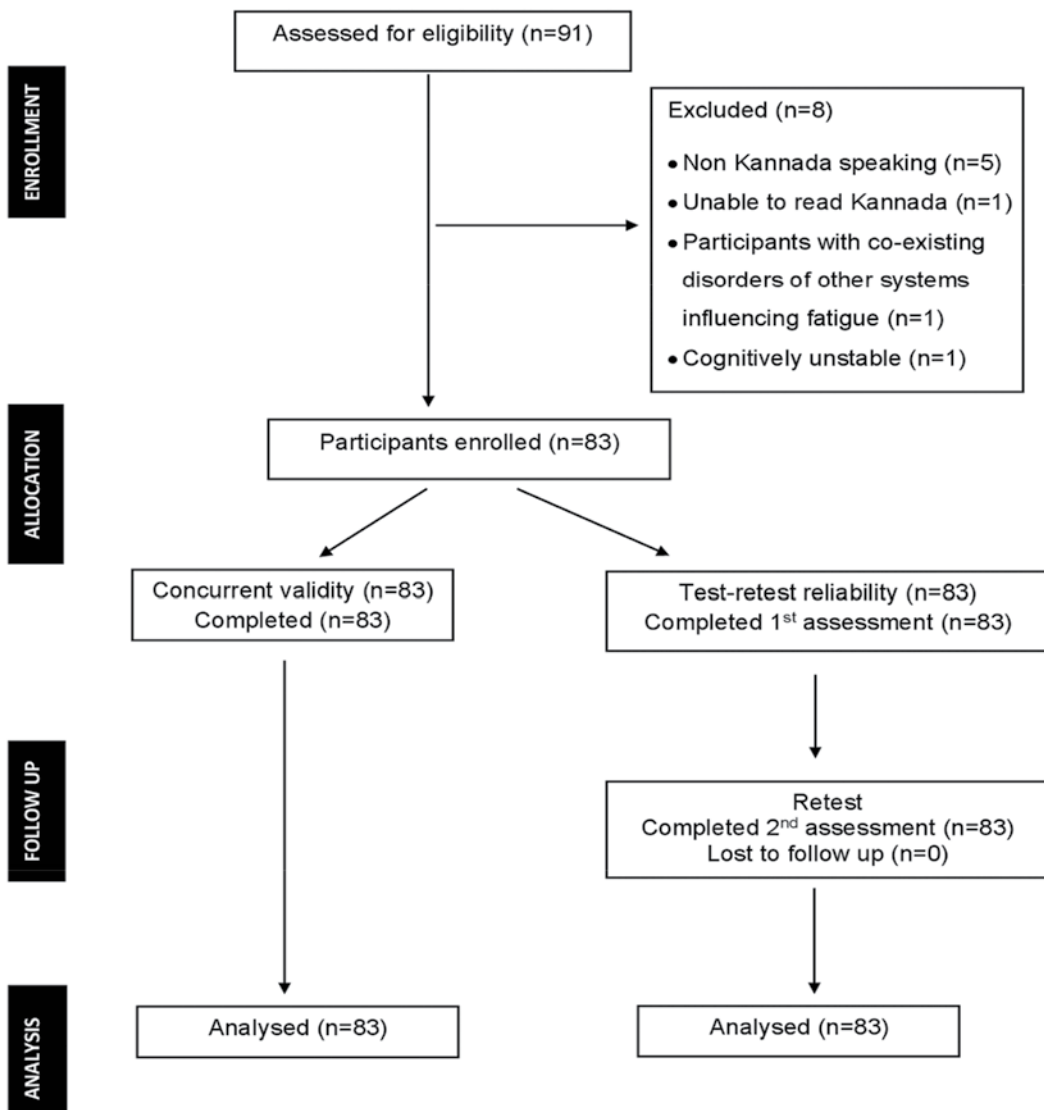
All the 5 individuals selected for cultural adaptation were able to comprehend the items and scoring criteria. They reported that all the items in the scale were simple and clear enough to be understood by any individual who could speak basic Kannada. However, 4 of these 5 individuals suggested the substitution of a synonym for the word "*satatavaagi*" ("sustained") in the 6th item of the scale, as it is not commonly used and is a little ambiguous. Hence the word "*nirantara*" ("continuous") was added, as it is simpler, commonly used and easily understood by the Kannada-speaking population. However, the translators felt that it was not necessary to add that word in the English version, as both words mean the same in English. Back translation to English was not considered necessary, since the addition of the synonym in Kannada did not change the meaning of the item. The Kannada version of the Fatigue Severity Scale was thus adapted by incorporating the change in item 6; this was further subjected to pilot testing.

The 30 participants included in the pilot study, with a mean (SD) age of 53.8 (11.7) years, had different neurological conditions: stroke (n=13), neuropathy (n=6), spinal cord diseases (n=3) and others (n=8). The majority of them were able to score all the items in the scale without any difficulty, except for item 1 and item 8. One participant was not able to understand the meaning of the word "motivation" in item 1, and two participants were not able to understand the meaning of "three most disabling symptoms" in item 8 of the scale. However, all the three participants were able to score these items with minimal prompting and cues. Hence, the frequency for all the items in the scale was 100%. The average time taken by the participants to complete the questionnaire ranged from 5 - 10 minutes. As the problems encountered during the pilot testing were very minimal, further changes were not made in the scale. Descriptive analysis was done to calculate the mean and SD of the total fatigue scores of all participants.

Concurrent Validity and Test-Retest Reliability of the Scale

Of the 91 individuals who were screened for eligibility, 83 participants were recruited. The selection procedure of participants in this phase of the study is shown in Figure 1).

Figure 1: Flow of Participants in the study



Demographic characteristics of the study participants are listed in Table 1.

Table 1: Demographic characteristics of study participants (n=83)

Characteristics	Value n (%)	Mean± SD
Age in years		51.1 ± 14.6
Gender		
Male	43 (51.8)	
Female	40 (48.2)	
Level of Education		
No schooling	2 (2.4)	
Primary school	54 (65.1)	
Secondary school	15 (18.1)	
Degree	10 (12.0)	
Post-graduation	2 (2.4)	
Marital Status		
Single	8 (9.6)	
Married	75 (90.4)	
BMI		22.6 ± 3.4
Employment		
Employed	39 (47.0)	
Not employed	44 (53.0)	
Diagnosis		
Stroke	38 (45.8)	
Neuropathy	14 (16.9)	
Spinal cord diseases	12 (14.5)	
Myopathy	5 (6.0)	
Others	14 (16.9)	
Disease Duration (in days)		549 ± 1523
Comorbidities		
Present	53 (63.9)	
Absent	30 (36.1)	
Sleep duration (in minutes)		490 ± 65.4

n - Sample size; SD - Standard deviation

Figure 2 describes the correlation between the Kannada version FSS scores and VAFS scores. There was statistically significant moderate correlation between the scores of the two scales ($r=0.71$, $p<0.001$).

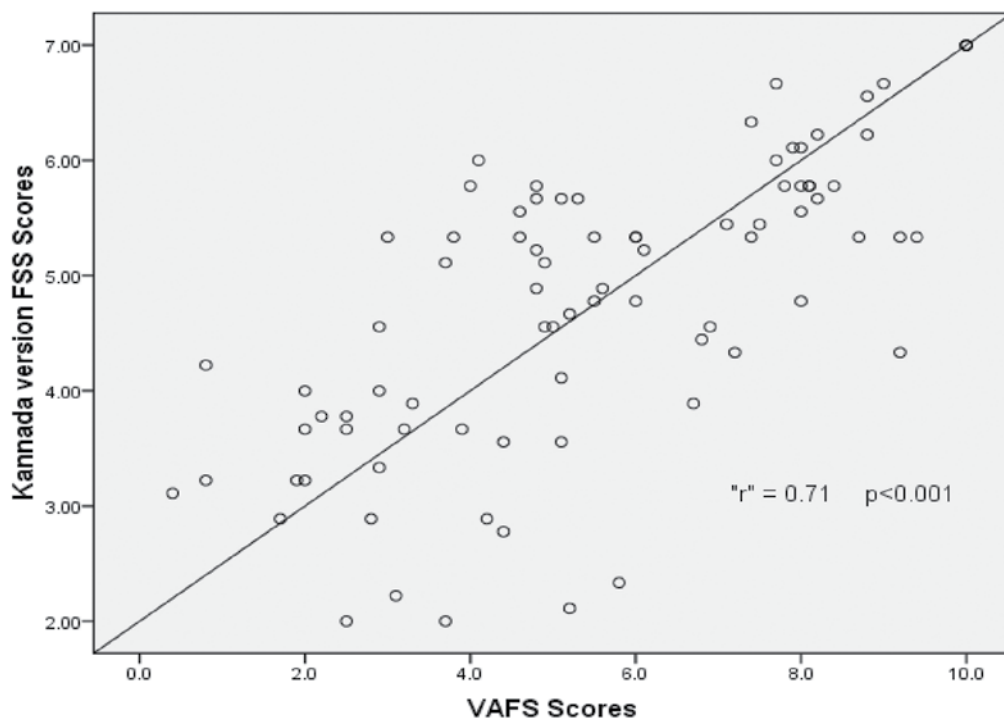


Figure 2: Correlation between the Kannada version FSS scores and VAFS scores

ICC of 0.92 with CI – 0.89-0.95 indicates excellent test-retest reliability of the Kannada version FSS. The ICC values of individual items and the total scores of the scale are listed in Table 2.

Table 2: ICC values for individual items and total scores of FSS

Items	Kannada Version FSS Mean Scores		ICC α (95% CI)
	Test	Retest	
1	5.7	5.3	0.80 (0.70 – 0.88)
2	4.6	4.4	0.78 (0.64 – 0.86)
3	3.2	3.2	0.83 (0.75 – 0.90)
4	5.1	5.3	0.80 (0.69 – 0.87)
5	4.7	4.0	0.57 (0.33 – 0.71)
6	5.2	5.2	0.77 (0.63 – 0.85)
7	4.8	4.8	0.73 (0.60 – 0.82)
8	4.8	4.2	0.86 (0.78 – 0.90)
9	4.8	4.7	0.74 (0.60 – 0.83)
Total	4.8	4.6	0.92 (0.88 – 0.95)

ICC- Intra-class Correlation Coefficient; FSS-Fatigue Severity Scale; CI- Confidence interval

No significant difference was observed when fatigue scores were compared across various neurological conditions. Mean scores of the Kannada version FSS for different neurological conditions are shown in Figure 3.

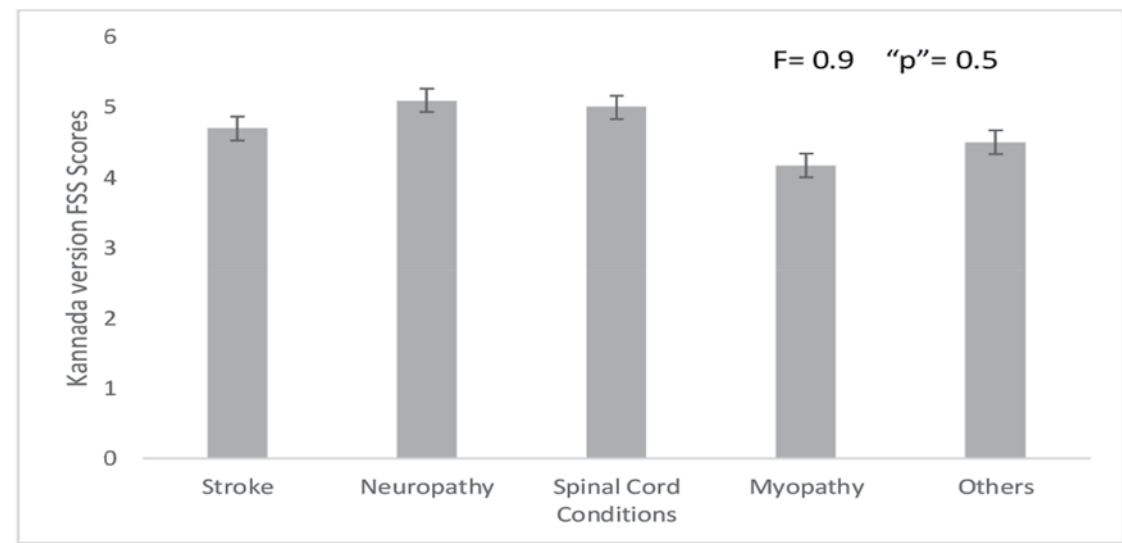


Figure 3: Mean scores of the Kannada version FSS for different neurological conditions.

The Kannada version FSS scores showed no correlation with disease duration, age, sleeping hours or gender of the participants with neurological conditions. The correlation coefficient values of various parameters with the Kannada version FSS is given in Table 3.

Table 3: Correlation of FSS scores with age, gender, sleep time and duration of the neurological conditions

Parameters	Mean (SD)	"r" value	"p" value
Duration	4.8 (1.26)	0.03	0.8
Age	4.8 (1.27)	0.23	0.04
Gender	4.7 (1.26)	0.20	0.8
Sleep time	4.8 (1.27)	0.07	0.4

SD- Standard deviation

DISCUSSION

Cross-cultural adaptation of self-reported scales in vernacular languages is of

great importance because the ability to understand the items in the scale is required for scoring appropriately, more so in self-explaining symptoms like fatigue (Beaton et al., 2000). Cultural adaptation of the scale was done with necessary adjustments targeted at the Kannada-speaking population in the present study. This ensured that the scale could be clearly perceived and comprehended by Kannada-speaking individuals.

The pilot testing of the Kannada version FSS among the Kannada-speaking population showed that the items within the scale were easily understood, indicating the clarity, feasibility and applicability of the scale. Furthermore, validity and reliability assessment of the scale revealed that it was an appropriate measure to quantify fatigue in the Kannada-speaking population with neurological conditions.

The results of concurrent validity are in line with the study done by Krupp et al. (1989) which showed moderate correlation of the FSS scores with VAFS scores among clients with Multiple Sclerosis and SLE. Similarly, Schanke et al. (2002) found FSS scores were correlated with VAFS among polio survivors. These results suggest that the Kannada version of this scale was able to detect fatigue as adequately as VAFS. However, evaluating fatigue among those with neurological conditions will be more effective with FSS due to the descriptions of nine different situations presented within the scale.

Test-retest reliability analysis of the Kannada version FSS showed good correlation and homogeneity among the items within the scale ($\alpha=0.92$). The findings of the present study complemented the results of previous studies done in India, e.g., in Hindi/Punjabi by Paul et al. (2016) and in Gujarati by Sharma and Sheth (2019), which showed good reliability in their respective populations. This suggests that the items within the scale reflected similar meanings and agreement during repeated evaluations of fatigue; and hence the FSS Kannada version could be used more conveniently to grade fatigue.

Fatigue is considered as an important contributor to poor quality of life (Havlikova et al., 2008). There are several factors, including duration of the disease, age, depression, existing comorbidity, sleep duration and so on among different neurological conditions which are assumed to contribute to fatigue (De Groot, Phillips & Eskes, 2003). Identification of factors that contribute to fatigue is important because it will lead to a better assessment and management of the symptom. In the current study, the diagnosis of participants did influence fatigue;

hence those diagnosed with neuropathy and spinal cord diseases showed more fatigue scores than other neurological conditions. These results are supported by earlier studies which revealed high prevalence of fatigue among clients with neuropathy (80%) (Merkies, Schmitz, Samijn, van der Meché & van Doorn, 1999; Merkies & Kieseier, 2016) and spinal cord diseases (37.2%) (Cudeiro-Blanco et al., 2017). Despite the absence of any proven reasons, demyelination and weakness in neuropathy could be the major factors for inducing fatigue in these populations (Garssen, Schillings, Van Doorn, Van Engelen & Zwarts, 2007); White, van Doorn, Garssen & Stockley, 2014). Similarly, sensory loss, pain and depression associated with spinal cord diseases could influence fatigue (Cudeiro-Blanco et al., 2017). These results are contrary to the belief of the current authors who anticipated greater amount of fatigue in stroke survivors than in those with other conditions. Even though post-stroke fatigue is highly prevalent, ranging from 25%-85% (Cumming, Packer, Kramer & English, 2016), the amount of fatigue may vary with type, severity and chronicity of the condition.

Despite more fatigue in chronic clients compared to acute and sub-acute phases, duration of the disease did not show any correlation with the fatigue severity scores. These results are contrary to an earlier study, which showed that increased duration of the disease contributed to fatigue in clients with stroke, brain injury and Parkinson's disease (de Groot et al., 2003). In the current study, the majority of participants admitted in the hospital were in the acute phase of a neurological condition and hence the data could have been skewed.

Factors including age and gender were assumed to affect the severity of fatigue; however, no correlation was seen with FSS scores in this study. Age could not be the sole factor for the presence and severity of fatigue, as perception of fatigue and fatigability increases with age but ability to recruit the muscle or firing rate is independent of age (Kalkman et al., 2008). Since FSS measures only the physical, social and cognitive aspects of fatigue (Krupp et al., 1989) and not the perceptual aspect, it might not be correlated to fatigue severity. The lack of association between fatigue severity scores and gender could be due to neurological conditions of the participants involved in the current study, which affected both genders equally.

Sleep disturbances are commonly observed in neuromuscular disorders, mainly due to the inability to change the position frequently at night, muscle twitches, jerks and disordered breathing due to involvement of the respiratory muscles. The common complaints reported by these clients were fatigue (83%) and daytime sleepiness (63%) (Labanowski, Schmidt-Nowara & Guilleminault, 1996).

However, this study did not show any association with sleeping hours as all the participants had an average sleep duration of eight hours per day, irrespective of different fatigue levels. Further lack of association could be explained because of the smaller number of participants with neuromuscular disorders. Several studies involving clients with recent stroke (Choi-Kwon, Han, Kwon & Kim, 2005) and Multiple Sclerosis (Armutlu et al., 2007; Labuz-Roszak, Kubicka-Baczyk, Pierzchala, Machowska-Majchrzak & Skrzypek, 2012) showed significant association of fatigue with depression. However, this could not be ascertained as the current study did not assess depression in participants. The inclusion of participants with all types of neurological conditions who were complaining of fatigue is considered as the strength of the study.

Limitations

Depression, which is considered to be one of the important factors resulting in fatigue, was not assessed in the study. Future studies could determine the association of FSS scores with depression in neurological conditions. Since there was a short time period (one day) between test and retest, there may have been a learning effect even though the items were rearranged in the FSS to limit the effect during the retest.

CONCLUSION

The Kannada version of the FSS has been culturally adapted to assess fatigue in the Kannada-speaking population and is a reliable and valid tool to assess severity of fatigue among individuals with neurological disorders in this linguistic population. In fact it could be used routinely as an efficient tool for effective assessment and management of fatigue in clients with all types of neurological conditions. The scale can be subjected to other psychometric properties such as responsiveness, to strengthen its clinical usefulness in this population.

ACKNOWLEDGEMENT

The authors are grateful to Dr Lauren B Krupp, MD Neurology, Paediatric MS Centre, NYU Langone, New York City, NY, USA, for permitting the validation of the Kannada version Fatigue Severity Scale.

They would also like to thank all those who readily agreed to participate in the study.

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Socioeconomic Factors Hindering Access to Healthcare by Persons with Disabilities in the Ahanta West Municipality, Ghana

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ABSTRACT

Purpose: *An estimated 15% of the world’s population lives with disabilities of various types and 80% of them are in low-income countries, with limited or no access to basic services including healthcare and rehabilitation facilities. The general objective of the study was to determine the socioeconomic factors that hinder access to quality healthcare by persons with disabilities in the Ahanta West Municipality of Ghana.*

Method: *A qualitative study was carried out. Purposive sampling was used to select the participants (persons with disabilities and healthcare workers). Data was collected through 10 in-depth interviews with health workers and 5 focus group discussions with persons with disabilities. Data was analysed based on the themes that emerged during the discussions.*

Results: *The major social factors found to hinder access to quality healthcare were cultural explanations of disability and its causes, stigmatisation, and attitudes of healthcare workers towards persons with disabilities. The economic factors that created barriers include costs of treatment and assistive devices, unemployment, poverty, and transportation problems.*

Conclusion: *A review of national health policy programmes and their implementation to ensure that the needs of persons with disabilities are adequately catered for. This study reveals that the current health policies and subsequent health services are not adequately considering the needs of persons with disabilities. It is recommended also, that there is the need for a change in attitude by the general public towards persons with disabilities. This in particular is a role of influential stakeholders such as government and religious institutions engaging on effective public education to bring to the*

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notice of the general public the meaning and cause of disability in order to reduce the way at which disability is explained from a cultural point of view.

Key words: *Persons Disability, Ahanta West Municipality, Socioeconomic, Healthcare Workers, Stigmatization, Ghana*

INTRODUCTION

It is estimated that about 15% of the world's population lives with a disability, and the number is increasing due to the rise in chronic diseases, injuries, car crashes, falls, violence and other causes such as ageing. Of this total, 80% live in low-income countries; most of them are poor and have limited or no access to basic services, including healthcare and rehabilitation facilities (World Health Organisation, 2006).

Disability is an inescapable human condition and at some point, almost every person is exposed to and may experience temporary or permanent disability (WHO & World Bank, 2011). Disability, evokes different social constructions, depending on the setting in which the concept is used. It is neither a social straitjacket nor a biological construct; instead, it is often hinged on the interactions among health, environmental and personal factors (WHO & World Bank, 2011).

Disability is an umbrella term covering impairments, activity limitations, and participation restrictions. An impairment is defined as a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations (WHO, 2010). Thus, disability is a complex phenomenon, reflecting an interaction between features of a person's body and mind as well as features of the society in which he or she lives such as inaccessible structures, disability unfriendly vehicles, etc. Disability is part of human life and people with disabilities can be found in any culture, and every community throughout the world. People are either born with a disability or acquire disability through circumstances and events such as disease, trauma and accidents (WHO, 2011).

Perceptions about health status may influence health behaviour, including utilisation of health services and the manner in which health needs are communicated. A study among people with epilepsy in rural Ghana, for example, found that spiritual beliefs surrounding epilepsy influenced health-seeking behaviour. Another study involving 380 people with epilepsy in rural areas of

the Gambia reported that only 16% of them knew that treatment was possible to prevent the occurrence of seizures; and of the 48% of people with epilepsy who had never used treatment, 70% did not know that clinics offered treatment for seizures (Coleman, Lopyy & Walraven, 2002; WHO, 2011). In another example, people who experience disability as they get older may “normalise” their (symptoms of) impairment as “just being part of ageing” rather than seeking appropriate treatment for their condition (Sontag, 2001). When the cause of a disease or impairment is not well-understood and is treated as a mystery, it tends to elicit fear from others (Sontag, 2001).

A healthcare system which ensures that everyone including persons with disability enjoy their right to healthcare has been referred to as ‘inclusive healthcare (Lindsey, 1992).’ In other words, such a healthcare system offers ‘an effective response to the needs of clients, not just in terms of treatment of health predicaments but also by addressing the overall well-being through understanding, informing, involving, counselling and respecting the individual (Lindsey,1992).

Objective

This study aimed to determine the socioeconomic factors that hinder access to quality healthcare by persons with disabilities in the Ahanta West Municipality of Ghana.

METHOD

Setting

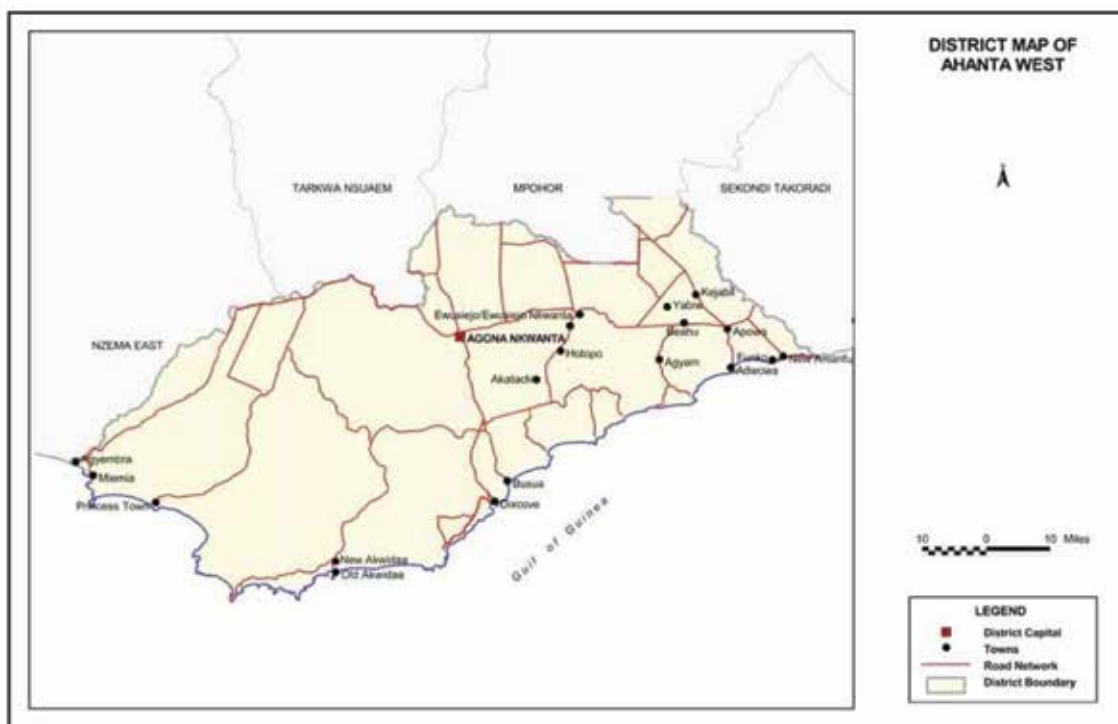
Ahanta West District is located at the southernmost point of Ghana and the entire West African Sub-Region, with its capital at Agona Nkwanta, also called Agona Ahanta (see Figure 1). The Ahanta West District has a land area of 591 square kilometres and a population of 106,215 people, according to the 2010 Population and Housing Census report. It represents about 2.5 % and 0.26 % of the surface area of the Western Region and Ghana respectively.

The district has one public hospital located at Dixcove, 4 health centres, 3 clinics and 12 Community Health-Based Planning compounds (CHPS). There are also 100 outreach points and a number of drug stores that are well patronised by members of the community. The proximity of the district to Takoradi enables many inhabitants, particularly those living in Apowa, New Amanful and Funkoe, to utilise health facilities in the Sekondi-Takoradi metropolis.

The district has one medical doctor and 103 nurses, which results in a low doctor to client ratio. The health sector in this district is not only confronted with inadequate health facilities, but also with inadequate numbers of personnel as many of them are reluctant to accept postings to remote areas without facilities, medicines, and medical equipment.

The district health authorities wish to improve access to quality maternal, child and adolescent health services, and intensify the prevention and control of non-communicable and communicable diseases. It also seeks to improve maternal mortality rates, reduce child mortality rates, combat HIV and AIDS and other diseases. Malaria continues to be the leading cause of outpatient morbidity and admission. Institutional mortality due to malaria has been drastically reduced and is no longer among the top ten causes of mortality for the year under review as a result of intensified malaria control interventions.

Figure 1: Map of Ahanta West District



Study Design

A qualitative study approach was adopted within the Ahanta West Municipality. Purposive sampling was employed to recruit the participants. In-depth interviews and focus group discussions were the tools used for data collection.

An inductive approach was used to group data in themes for easy coding and analysis, guided by the research questions and objectives.

Study Sample

The purposive sample comprised of persons with disabilities and leaders of the various Organisations of People with Disabilities (OPDs) who were registered with the Department of Social Welfare under the Ministry of Gender, Children and Social Protection. In addition, 10 healthcare workers employed at the Agona Health Centre in the Ahanta West Municipality participated in the study. All people participated on a voluntary basis.

Data Collection

Structured in-depth interviews and focus group discussions were used in collecting information from the respondents. To ensure confidentiality and anonymity, the researchers did not record identifiers such as names, street addresses and contact numbers of respondents.

Focus group discussions were held on two different days. In order to accommodate all the individuals involved, one of the focus group discussions was deliberately organised with males only and one was only for females; the remaining three consisted of mixed groups. Only interviews were used to collect information from the health workers, as it was difficult to get them together at the same time, in one place, for a focus group discussion. It was also important to avoid disrupting their work.

Recording of the proceedings on audiotapes took place to guide the transcription and translation of responses.

Data Analysis

Qualitative study methods allowed for more in-depth discussion of issues, thereby providing opportunities for the interviewees to present details of phenomena which are difficult to convey when using quantitative methods

with, for instance, standardised questionnaires. Since most of the discussions were in the local dialect (Fante), translation was needed from Fante to English. The audiotapes and field notes taken during the interactions were compared with the translated version of the data to ensure that the transcriptions presented the true meaning of the participants' responses. After the translation and editing, the agreed-on data was grouped into headings or themes for easy coding, identification, and analysis. The research objectives and questions guided the researcher in categorising the edited information into presentable formats based on the various themes. Similar responses were put under the same headings in the various categories that were developed. The coding was inductive.

Parts or segments of texts or quotes that are related to the interpretations will be paraphrased and presented in the findings.

Ethical Issues

Ethical approval was obtained from the Committee on Human Research, Publication and Ethics at the Kwame Nkrumah University of Science and Technology, School of Medical Sciences. Respondents were informed that the information retrieved was for academic purposes. They were assured of confidentiality and anonymity.

RESULTS

Demographic Characteristics

The demographic characteristics of the people with disabilities who took part in the focus group discussions are presented in the following two Tables.

Table 1: Demographic Characteristics of the People with Disabilities

Variables	Frequency (n=33)	Percentage (%=100)
Age Group		
Below 20 years	8	19
20-29 years	11	25
30-39 years	16	37
40 years and above	8	19
Sex of Respondents		
Male	24	56
Female	19	44
Religion of Respondents		
Christianity		
Islam	23	53
Traditional	11	26
Other	4	9
	5	12
Disability Type		
Mobility		55
Sight	18	18
Hearing	6	9
Other	3	18
	6	

Table 2: Demographic Characteristics of the Interviewed Healthcare Workers

Variables	Frequency (n=10)	Percentage (%=100)
Position of Healthcare Workers		
Senior staff	6	60
Junior staff	4	40
Unit/Department of Healthcare Workers		
Administration	2	20
Nursing	5	50
Medical	2	20
X-ray	1	10

Social Factors hindering Access to Quality Healthcare by Persons with Disabilities

Several social factors were identified by persons with disabilities as major hindrances for them to access quality healthcare.

Cultural Interpretation of Disability

The cultural interpretation of disability appears to play a major role in determining whether persons with disabilities would access healthcare or not. Persons with disabilities who participated in this study believe that most disabling conditions are caused by individuals' disobedience to norms such as going to the farm on Thursdays, or violation of taboos such as going to the sea for fishing activities on Tuesdays. It is therefore important that the individual with the disabling condition appreciates this and asks for forgiveness from God or the Gods, rather than seeking help from modern healthcare facilities.

"...Most people believe that we are disabled because our forefathers and family members did something wrong against the Gods by disobeying them and we are paying the price" (Male respondent, focus group discussion).

"...I think that some of them are as a result of their parents' or their own disrespect for norms and traditional rules in their communities, that is why they are suffering from disability" (Healthcare provider, individual interview).

Attitudes of Healthcare Workers towards Persons with Disabilities

The study reveals that attitudinal factors among personnel working within the healthcare system hinder access to quality healthcare. Some of these are: verbal abuse of persons with disabilities, lack of cross-cultural understanding of disability due to different cultural backgrounds of some of the healthcare workers, and communication difficulties between hearing and speech impaired persons and healthcare workers.

Abuse and Maltreatment of Persons with Disabilities by Healthcare Workers

Most of the persons with disabilities pointed out that attitudes and behaviour of health workers, especially the way they relate and talk to them, is shameful. They report various incidents where different categories of health care workers pass derogatory comments about them.

“...I was pregnant and went for antenatal care, and a nurse looked at me and said, ‘you too, you have feelings?’ She went further to say that I should check myself before I do certain things. This really hurt me, and I never went to that hospital again” (Female respondent, individual interview).

“...I went to the hospital with my wife, and when we went to the consulting room, the look on the doctor’s face alone told me that she was surprised to see that my wife who is non-disabled married a person with disability like me” (Male respondent, focus group discussion).

“.....I have a similar experience. I remember a doctor requested to see my husband privately and when he came back, he said the doctor asked him what influenced his decision to marry me” (Female respondent, focus group discussion).

The emotional abuse of persons with disabilities was not only expressed by persons with disabilities themselves but also by healthcare providers. Some of the hospital staff indicated that they had also witnessed their colleagues verbally abusing persons with disabilities who come to the hospital.

“...Some of my colleagues laugh at persons with disabilities who come to the hospital for treatment, especially disabled women who come to the hospital and are pregnant” (Male healthcare worker, individual interview).

“.....I remember some time ago a person with disability reported one of our staff to us, about how harsh the staff talked to him. We at the administration hear some of these cases but are not many and frequent” (Hospital administrator, individual interview).

Shunning and Avoiding Persons with Disability

Most healthcare providers, particularly the nurses, stated that if they would be given the option they would avoid interacting with persons with disabilities. The reason they gave was that most people with disabilities are difficult to work with, and some of them are impatient. However, because it is exceedingly unprofessional to do so, they unwillingly treat and work with them.

“...Truly speaking, if I have my own way, I would not work with any person with disability because most of them are very aggressive and violent to some extent” (Healthcare provider, individual interview).

“...Do you know that most of these persons with disability are impatient and always want to have their way out even if they come to meet other people?”(Healthcare provider, individual interview).

The revelations by the health workers concerning shunning and avoiding persons with disabilities at the hospital were no different from what persons with disabilities stated. Persons with disabilities explained how health workers deliberately avoid them at the hospital.

“...Some of the nurses do not sometimes want to take your folder to a doctor for you to be treated just because you are physically different from them” (Female respondent, individual interview).

Communication Barriers between Persons with Disability and Health Workers

The study discovers that most of the health workers were not able to understand the culture and language of certain individuals or communities of persons with disabilities. They are sometimes unable to explain the results of the diagnosis and prescriptions to the clients with disabilities. This lack of communication becomes more difficult when the clients are hearing impaired. Health workers are often unable to communicate in sign language and cannot understand the local dialect if they are not from the same region as the persons with disabilities.

“...It is difficult to explain things to the hearing impaired persons and this hospital does not have sign language interpreters to help us explain diagnosis and prescription to them when they come to the hospital” (Health worker, individual interview).

“...Healthcare providers do not appreciate our conditions and are unable to give us full information about our condition and what to do” (Female with disability, individual interview).

Stigmatisation of Disability

As a result of the various cultural interpretations associated with disability, most of the persons with disabilities face stigmatisation especially if they have intellectual disability. Stigmatisation comes not only from their family members but also from their friends and members of the larger society. When people see persons with a disability at the hospital, they are surprised. The study respondents indicated that individuals who belong to families with strong cultural beliefs and

traditional rules suffer from stigma the most. Such stigma discourages people from seeking care for health problems, be it related to their disability or not.

"...When people see me at the hospital, they murmur among themselves 'Ah, you are wasting our time, you are a nut and you are this and you are that,' so at the end of the day I do not find it pleasant to visit the hospital" (Female respondent, focus group discussion).

"...That is true!(referring to the previous speaker) I remember I went to a hospital and the nurse asked the people who were going to see the doctor to allow me to go first, and the kind of statements and insults poured on me after the nurse had left deterred me from going back to the same hospital for further check-ups and treatment"(Male respondent, focus group discussion).

Religious Interpretation of Disability

Another social factor linked to cultural beliefs is the religious interpretation of disability. Since disability is often explained from a spiritual point of view, most persons with disabilities tend to visit traditional healers in their communities for treatment.

The reason for this is the culturally specific belief that traditional healers are called by the Gods to help their communities (*dunsinyi*) and therefore have power to free people from spiritual illness.

"...I was taken to a traditional healer in my hometown for about one year without any improvement. My family members thought that I could be healed by the man, but my condition was still worsening. When we later visited the hospital, I was told that my vision could have been saved if I had come earlier for surgery" (Female respondent, individual interview).

"...I do not attend modern hospitals because their treatments are unable to change my condition. I will rather go to the herbalist for treatment instead of hospital because that is where I believe my healing can come from" (Male respondent, focus group discussion).

Some of the respondents revealed that they were Christians and visited the prayer camps for healing rather than the hospital. They also hold the belief that disabling conditions can best be treated or handled by spiritual men of God who have been given the power to cast out demons responsible for the intellectual disability.

“...I attend prayer meetings and prayer camps for healing whenever I am sick. This is because I believe that sometimes our sickness is not something that hospital medicine can cure, especially we persons with disabilities” (Female respondent, focus group discussion).

This study revealed that if the treatment does not improve the client’s condition, he or she eventually decides to use a public health clinic, sometimes accompanied by family members or even by the traditional healer due to beliefs that their disability is the result of a spiritual attack on the person with the disability.

Inadequate Information

The study found that there is inadequate information and knowledge in society concerning the (treatment of) certain disabling conditions, especially about mental health. The public is often not aware of rare disabling conditions and therefore do not seek treatment from healthcare services. The respondents see this partly because of policies and healthcare reforms being focused on general health-related problems without giving any attention to disability and the health-related needs of persons with disabilities.

“...Madam (referring to the facilitator), do you think that there is any hospital in Ghana that can cure my illness? If you do, please tell me because I do not think my condition can be reversed” (Female respondent, focus group discussion).

This study shows that most persons with disabilities do not have adequate information about relevant medical treatment and proper use of prescribed medicines. They indicated that there were times when they were reluctant to take their medicine due to (assumed) side effects (such as impotence) or due to the fact that they did not trust or believe that the medication would actually be of help.

“...Truly speaking, I remember some time ago I went to the hospital, and when I came home and told a friend about the prescribed drugs, he said those drugs are ineffective and cannot treat my ailment since he had that condition previously and the drug didn’t treat the ailment, so out of fear, I dumped the drugs and went to a nearby pharmacy to get painkillers for myself” (Male respondent, individual interview).

Economic Factors hindering Access to Quality Healthcare by Persons with Disabilities Several economic reasons were identified as major factors hindering access to quality healthcare by persons with disabilities in the Ahanta West

Municipality. They included high levels of unemployment among persons with disabilities, high cost of treatment and assistive devices, and the unavailability of accessible and affordable transport.

Unemployment

Persons with disabilities identified that unemployment hinders access to quality healthcare by persons with disabilities. They indicated that most of them are not employed and for that matter do not have the money to go to hospital for treatment even when they are ill.

“...Menyiadwuma biarayε (meaning - I do not have a job) so in times when I am sick, I am unable to go to hospital for the needed treatment” (Female respondent, individual interview).

Cost of Treatment and Assistive Devices

High unemployment and consequent poverty means that many persons with disabilities are unable to pay their hospital bills. Most of them indicated that they do not go to hospital regularly for this reason. They are aware of the existence of health facilities, but the costs involved in accessing the services provided by these hospitals usually prevents them from seeking healthcare.

At every stage of a hospital visit, from obtaining a hospital card or folder until visiting the dispensary, one has to pay money even if one possesses a health insurance card. If surgery is involved, it becomes even more difficult to have the surgery. The average cost of visiting a hospital is GH¢50–GH¢100 (\$8.61-\$17.22) per visit. This, according to them, is expensive and they cannot afford such high costs.

“...It is not that I would not like to go to the hospital, but if I go, who will bear the cost involved? I therefore visit the local drugstore and get some pain killers for myself” (Female respondent, focus group discussion).

“...I will go to the hospital regularly if the government makes it free for those of us who are disabled. Otherwise, modern hospital will not be a preferred place of treatment for poor people like me,” (Female respondent, focus group discussion).

Some of the respondents also indicated that assistive devices are costly, and they are unable to purchase them. They revealed that there was no point in going to the hospital if they were told to buy assistive equipment that they could

not afford.

“...I was told to get a pair of crutches to aid my movement but because of the cost, I am still using this stick” (Male respondent, individual interview).

Transport

Lack of transport was identified as one of the economic reasons for persons with disabilities not accessing healthcare. Persons with disabilities pointed out that they found it difficult to use public transport due to the inaccessible nature of these commercial cars. There is not enough space to accommodate them and their assistive devices, especially if they are wheelchair-users. The embarrassment of being carried on somebody's back or in their arms and being pushed in their wheelchairs to distant hospital locations are deterrent.

“...I find it difficult to board cars to aid my movement, all because of my wheelchair. So, when I am sick, I stay at home and send people to go and buy drugs for me just to avoid the difficulty of boarding commercial cars (Female respondent, individual interview).

DISCUSSION

Social Factors influencing Access to Healthcare by Persons with Disabilities

Several social factors were identified that influence access to healthcare by persons with disabilities. Notable among them were cultural interpretations of disability, stigmatisation due to disability, inadequate information, and spiritual explanations of disability. Cultural explanations of disability played a major role in determining whether persons with disabilities would access healthcare or not. The cause of disability is usually explained from the cultural and belief systems of people. The study respondents believed that most disability was caused by individuals' disobedience to norms or violation of taboos. It was therefore important that the individual with the disability acknowledge this and ask for forgiveness from the Gods, rather than visit modern hospitals for healthcare. This was similar to the findings of Dodor (2009) who studied stigma as a result of tuberculosis, in Ghana, and found that people explained the cause of tuberculosis from a cultural perspective. When the cause of a disease or impairment is not well-understood and is treated as a mystery, it tends to elicit fear from others (Sontag, 2001).

As a result of the various cultural interpretations associated with disability, most persons with disabilities face stigmatisation, especially those with intellectual disability. The stigmatisation is not only by their family members but also by their friends and members of the larger society. When people see them at the hospital, they are surprised. The respondents indicated that individuals who belonged to families with strong cultural beliefs and traditional rules suffered the most. Such stigma discourages people from seeking care for disability health-related problems.

Another social factor linked to cultural beliefs is the religious interpretation of disability. Since disability is generally explained from the spiritual point of view, most persons with disabilities tend to visit traditional healers in their communities for treatment. The reason for this is the culturally specific belief that traditional healers are called by the Gods to help their communities (*dunsini*) and therefore have power to free people from spiritual illness. Some of the respondents also revealed that they were Christians and visit the prayer camps for healing rather than going to hospital.

The study found certain attitudinal factors within the healthcare system that influence access to healthcare by persons with disabilities. Some of the attitudinal factors were: abuse of persons with disabilities, lack of cross-cultural understanding, maltreatment of persons with disabilities, and communication problems between persons with disabilities and healthcare providers. Most of the respondents pointed to the shameful attitudes and behaviours of health workers towards persons with disabilities, especially the way they relate and talk to them.

The study found that there was inadequate information and knowledge in society concerning the ability to treat certain disabling conditions, especially in the field of mental health. The general public is often not aware of rare disabling conditions and the importance of timely interventions, and therefore they do not seek healthcare services. In relation to inadequate information, the study found that most persons with disabilities do not have adequate information about medical treatment and the use of prescribed drugs. They indicated that they were sometimes reluctant to take their medicine due to side effects (such as impotence) or due to the fact that they did not trust or believe that the medication would actually help. The respondents see this partly as a result of policies and health reforms being focused on general health-related problems of the people without disability, while paying little attention to persons with disabilities.

When there is uncertainty about how a disease is transmitted, the multiple interpretations of the cause and spread that ensue have the propensity to fuel stigmatisation of individuals suffering from the disease (Ogden and Nyblade, 2005).

Economic Factors hindering Access to Quality Healthcare by Persons with Disabilities

Several economic reasons were identified as the major factors that hinder access to quality healthcare by persons with disabilities in the Ahanta West Municipality of Ghana. They included: high unemployment among persons with disabilities, high cost of treatment and assistive devices, and transportation.

Unemployment among persons with disabilities was identified as an economic factor that influences their access to healthcare. Most of the study participants were not employed and for that matter did not have money to visit hospital for treatment when they were ill. As a result of unemployment, most of them were relatively poor and could not meet their basic needs, including affording quality healthcare.

The study found that the cost involved in the going to the hospitals scared away persons with disabilities. Unemployment and poverty among persons with disabilities left them unable to pay their hospital bills. Most of them were aware of the health facilities, but the cost involved in accessing the services provided by these hospitals always prevented them from going there. From start to finish – from hospital card or folder to dispensary - at every stage one had to pay money even if one had a health insurance card. The hardest part was when surgeries were necessary. This finding is not different from the review of the 2002–2004 World Health Survey which revealed that affordability was the primary reason why people with disabilities, across gender and age groups, did not receive needed healthcare in low-income countries. For 51 countries, 32%–33% of men and women without disability could not afford healthcare, compared to 51%–53% of people with disabilities. Transport costs also ranked high as a barrier to accessing healthcare in low-income and middle-income countries, and across gender and age groups (WHO, 2011).

Some of the respondents also indicated that the cost of assistive devices was very high and they were unable to purchase them. They revealed that there was no

point in going to the hospital if one was told to buy assistive devices and could not meet the cost.

The lack of transport was identified as one of the economic reasons for persons with disabilities not accessing healthcare in general. Persons with disabilities – especially with difficulty in moving- pointed out that they found it difficult to use public transport due to the inaccessible nature of these commercial cars. They did not have enough space to accommodate them and their assistive devices, especially if they were wheelchair-users. The embarrassments of being carried in somebody's arms or on their back, and of being pushed in a wheelchair to distant hospitals, were deterrents. The WHO (2011) report that transport for people with disabilities is often limited, unaffordable or inaccessible, also supports this finding.

CONCLUSION

The study found that there were several social factors that hinder persons with disabilities' access to quality healthcare in the Ahanta West Municipality, Ghana. The social factors that hinder access to quality healthcare by persons with disability were: inadequate information about treatment and healthcare, preferred consultation with traditional healers as well as prayer camps, stigmatisation of disability, cultural explanations of disability that regard disability as a result of punishment, juju, sorcery and magic or charms from the Gods.

Various economic reasons were identified as the major factors that hinder access to quality healthcare by persons with disabilities. They included: high unemployment among persons with disabilities, cost of treatment and assistive devices, and transportation. Most of the respondents were not employed and did not have money to attend hospital for treatment when they were ill. As a result of unemployment, most of them were relatively poor and could not meet their basic needs in life which included quality healthcare.

The study found certain attitudinal factors within the healthcare system that influence access to healthcare by persons with disabilities. Some of the attitudinal factors were: abuse of persons with disabilities, lack of cross-cultural understanding, maltreatment of persons with disabilities, and communication problems between persons with disabilities and healthcare providers.

Recommendations

In view of the study findings, the following recommendations have been made.

1. Stakeholders such as the government and NGOs must embark on effective public education to bring to the notice of the general public the meaning and causes of disability; thereby reducing the prevalent cultural perspectives of disability.
2. Public education must also be extended to health professionals in order to reduce stigmatisation of disability which results in abuse and maltreatment of persons with disabilities by healthcare providers.
3. It is recommended that Government policy exempts all persons with disabilities from paying for medical care. This will ensure that the cost of accessing healthcare, which continues to be a burden among persons with disabilities, will be addressed.
4. The Ministry of Health should ensure that at every district, regional and training hospital there are health professionals who have received detailed training on working with persons with disabilities. This will help to promote good relationships between healthcare workers and persons with disabilities. It will also enhance effective communication between them.

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Challenges Associated with Vocational Rehabilitation for Persons with Disability in the Kumasi Metropolis of Ghana

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ABSTRACT

Purpose: *The study examined the challenges associated with vocational rehabilitation for persons with disabilities in the Kumasi metropolis of Ghana. It assessed the support available for vocational rehabilitation delivery centres and suggested measures that could ensure effective delivery of services to persons with disabilities.*

Method: *The study design was descriptive and qualitative. Purposive sampling was used to select 4 heads/managers and 11 tutors from four institutions offering vocational rehabilitation services for persons with disabilities. Interviews were conducted with the aid of semi-structured interview guides. Data was transcribed from audio-recordings and analysed using a thematic approach. The themes and codes are presented as findings and supported by quotes.*

Results: *The study revealed that the vocational rehabilitation centres in the Kumasi metropolis face challenges such as: insufficient finance, infrastructure deficits, inadequate teaching and learning materials, and stigmatisation of staff members. To counter these, participants proposed: prompt payment of government grants, increasing staff motivation, improvement in infrastructure, provision of adequate tools and equipment for teaching, and posting of additional tutors.*

Conclusion and Implications: *The government of Ghana, through the Ministry of Education, must restore the goods and services grants, as well as administrative grants, and minimise delays in the release of funds. Non-governmental organisations that work towards funding disability-related*

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activities should redirect their focus towards vocational rehabilitation for persons with disabilities.

Key words: vocational rehabilitation, persons with disabilities, Ghana.

INTRODUCTION

Individuals with disability may experience restrictions in accessing certain environments that are necessary for their education, for improving work performance, or training. If they have limited opportunities for education and training during their childhood and youth, it subsequently weakens their preparation for work (Elliott & Leung, 2005). Those who are confronted with such conditions often face financial hardship and are at a higher risk of psychosocial problems (Price, 2003). The aim of vocational rehabilitation programmes is to enable individuals with either temporary or permanent disability to access, return to or remain in employment. Vocational rehabilitation aims at maximising the ability of an individual to return to meaningful employment (British Society of Rehabilitation Medicine, 2003). Similarly, Tsengu, Brodtkorb and Almnes (2000) stated that early vocational skills training increases self-confidence and raises self-esteem and perfection, which enhance effective task performance during future working life.

Aware of the benefits associated with vocational rehabilitation for persons with disabilities, many countries devote significant resources to various rehabilitation programmes aimed at securing employment for people with disabilities (Fevang, Markussen & Røed, 2014). The United States' State-Federal Rehabilitation Service programme alone spends more than US\$2.5 billion annually; this is instrumental in helping people with disabilities to acquire the necessary training to gain and retain employment. However, Fevang et al. (2014) indicate that the success of delivering these services has been limited so far. Despite the numerous advantages that vocational rehabilitation may have for persons with disabilities, the British Society for Rehabilitation Medicine (2003) concluded that vocational rehabilitation services are, at present, woefully inadequate in terms of scope, content and standard in developing countries, among which Ghana is included. As explained further by Sweetland (2012), the development of vocational rehabilitation services in low-income countries has been piecemeal, uncoordinated, lacks adequate resources and investments, and is inadequate for society's needs, especially for persons with disabilities.

Vocational rehabilitation programmes have difficulty in achieving their aims due to a lack of resources, especially in low-income countries, as the leadership is usually not committed or able to sufficiently fund vocational rehabilitation (Lawrence, Mears & Duben, 2009). The situation in Africa is appalling. Tsengu et al (2000) has shown that the number of vocational rehabilitation centres is very limited in many African countries. This is true of Ghana, where the few vocational rehabilitation centres do not have curricula that is appropriate for the special vocational needs of persons with disabilities. In Nigeria, Ngobeni (2015) observed that there is inadequate funding for the delivery of vocational rehabilitation, which has resulted in lack of resources to conduct practical and effective training, such as textbooks, equipment and tools, or raw materials needed to practice. Some other problems that have been identified in African countries are poor facilities for staff, pathetic condition of services, and lack of adequate equipment for the implementation of meaningful vocational rehabilitation programmes (Obioka, 2011; Ngobeni, 2015). According to Hawley (2012), shortage of classrooms or old infrastructure and limited space also make it difficult for the implementation of vocational rehabilitation programmes. Howard (2009) indicated that a poor learning environment also poses a serious challenge to the successful implementation of vocational rehabilitation programmes. Another factor is the quality of personnel who deliver the training. It has been argued by Howard (2009) that the lack of qualified or specialised trainers to carry out vocational rehabilitation programmes is one of the major barriers to its success. Obioka (2011) discovered that, in Nigeria, vocational rehabilitation programmes are conducted by unqualified educators who are ill-equipped in terms of knowledge and skills required to shape the future work habits of persons with disabilities. Ngobeni (2015) also indicated that persons with disabilities receive insufficient and inadequate vocational training due to a lack of qualified trainers. Again, the Special Education unit of Ghana Education Service lacks adequate staff to assist in the area of vocational rehabilitation for persons with disabilities. According to Casely-Hayford and Lynch (2003), cited in Okyere (2009), “the majority of the graduates who majored in special education from the University of Education in Winneba, end up teaching in mainstream schools or leave the teaching profession altogether”. They further indicated that, “most disaffected teachers do not want to teach students with special needs education but simply wish to obtain a degree or diploma when they enter the University of Education, Winneba”. This might be the result of poor motivation to become special needs educators. Ngobeni (2015) reported that the support and motivation provided to the management

and training staff in vocational rehabilitation institutions were insufficient for effective delivery of services.

Earlier, Costelloe and Langelid (2011) had argued that a lack of motivation among trainers and previous negative experiences of vocational rehabilitation training were major factors responsible for trainers' inability to deliver effective services to people with disabilities in vocational rehabilitation centres. Therefore, vocational rehabilitation training opportunities must be organised for teachers, and they should be given attractive allowances so that they do not opt for mainstream education work. According to Okyere (2009), an additional number of training years should be a requirement for those who, after graduation, want to work as vocational trainers with persons with disabilities.

Research has largely focused on the state of special schools in Ghana and the relevance of vocational rehabilitation courses to persons with a disability, but scarcely refers to factors that affect the outcomes of such training for persons with disabilities. Persons with disabilities hardly access the labour market and economic benefits due to their lack of qualifications and discrimination from employers (Choruma, 2007). Therefore, unsuccessful vocational rehabilitation service delivery may leave persons with disabilities with no option but to continue depending on charity and unable to become fully integrated into the mainstream of society due to lack of required skills to compete in the labour market (World Health Organisation, 2011).

Objective

The current study aimed to determine the support available for vocational rehabilitation delivery, the various challenges encountered by vocational rehabilitation centres, and the measures that can be put in place to ensure effective delivery of vocational rehabilitation services to persons with disabilities. To this end, the research focused on the challenges associated with vocational rehabilitation for persons with disabilities in the selected rehabilitation centres of the Kumasi metropolis, Ghana.

METHODS

Study Design

A qualitative and descriptive design was adopted. Ary et al. (2002) believed that this approach helps to understand both human and social behaviour from an “insider perspective”, resulting in a vivid description of phenomena.

Study Sample

Fifteen participants were selected using a combination of purposive and convenience sampling techniques. Purposive sampling was necessary since a category of the sample was considered to be in the best position to provide specific information. These included heads of selected institutions which provide vocational rehabilitation (Edwinase Rehabilitation Centre, Kumasi Cheshire Home, Garden City Special School, and Deduako Life Community School), and their tutors/staff members. While the institutional heads were automatically included in the study, the other participants were selected if they had a minimum of 2-years work experience in their respective institutions. The number of participants was sufficient to reach a point of saturation.

Data Collection

Individual interviews, lasting for 25 – 30 minutes, were conducted with the aid of semi-structured interview guides. Interviews were considered the best option in terms of cost and time. They were held between the second and fourth weeks of March 2018 at Edwinase Rehabilitation Centre, Kumasi Cheshire Home, Garden City Special School, and Deduako Life Community School.

Data Analysis

Interviews allowed participants to express their views and the researchers did the necessary probing to get a clearer understanding of the issues raised.

The researchers listened to the recording of each interview 3 to 4 times before transcription, and then cross-checked the transcripts with their respective audio-recordings to make sure that all information was appropriately captured. This was followed by coding, based on the dominant themes, and finally analysis of the data. Participants have been quoted as and when appropriate.

Ethical Considerations

Approval was granted by the Committee on Human Research, Publications, and Ethics of Kwame Nkrumah University of Science and Technology in Kumasi. Participation in the study was voluntary and participants were at liberty not to answer questions at any stage of the interview. Anonymity was assured by the removal of all identifiers from the research instrument. The complete data of this work can be obtained from the Department of Community Health, School of Medical Sciences, Kwame Nkrumah University of Science and Technology

RESULTS

Demographic Information of Participants

As shown in Table 1, 73% of the participants were males. While 54% of the participants were teachers by profession, 20% were headmasters of the schools, 13% were psychiatric nurses and 13% were administrators. In terms of work experience within their institutions, 67% had worked for more than five years while 33% had worked for less than five years. Regarding educational levels, 33% of the participants had a Master's degree, 27% had a Bachelor's degree and 40% were diploma-holders.

Table 1: Demographic Characteristics of the Study Participants

Category	Frequency (n)	Percentage (%)
Sex		
Male	11	73
Female	4	27
Total	15	100
Position		
Headmaster	3	20
Administrator	2	13
Psychiatric nurse	2	13
Teachers/Tutors	8	54
Total	15	100
Qualification		
Master's Degree	5	33
Bachelor's Degree	4	27
Diploma	6	40
Total	15	100

Special Education background		
With SPED	6	40
Without SPED	9	60
Total	15	100
Working Experience (years)		
1-2	3	20
3-5	2	13
6-10	6	40
11-above	4	27
Total	15	100

Source: Authors' fieldwork (2019)

Available Support for the Delivery of Vocational Rehabilitation for Persons with Disabilities

Data analysis showed that support for the delivery of vocational rehabilitation was largely in the form of feeding grants, goods and services grants, and provision of teaching and learning materials. The sources of support were the government, benevolent organisations, and individuals.

"... I think you are aware that there is a government school. So, we do get support from the government. The kind of support we get from the government is: the government feeds the students. The government also gives us other things. Even as you see, the bus there was given to us by the government. So, these are government supports and in case we need teachers or other personnel, it is the government who sends them here" (Participant D3).

"...Here the school is a government institution and therefore being funded by the government of Ghana. The government gives a feeding grant so that we can feed the students. Initially, three grants were given by the government: feeding grants, administrative grants, and services grants. But unfortunately, two of the grants have been cancelled so we are only depending on feeding grants. Apart from the feeding grants we also depend on donors, philanthropists, and caregivers (parents and other relatives) of persons with disabilities here. Sometimes when they come to visit, they also support us and the items they bring also help us to manage the school" (Participant GC4).

These supports, though very useful, were inadequate and were not supplied regularly.

"...As for government's [support], it is supposed to be every term, but with the problem that we have, government is not able, not one government, all government that comes and goes, there is always one problem or the other. The things will delay, delay, and delay before they will come. So, they do come but it delays" (Participant D3).

"...Ok, sometimes within a whole year, we have two groups of people coming to help. We are in the second term, and we've only had a [married] couple coming in to donate some clothes, fabric for the tie and dye, and also wax for candle making. Our main support which is supposed to be from the government is even more delayed "(Participant D2).

"...The support comes once in a while. But when it gets to festive seasons, like Christmas and the likes, a lot of people and organisations come in to donate. But aside that, normal time it is once in a while that some groups come in to donate" (Participant EC3).

Challenges associated with Vocational Rehabilitation for Persons with Disability

The main themes that emerged were financial challenges, infrastructure and facility challenges, human resource challenges, and personal challenges.

Financial Challenges

All the participants revealed that vocational rehabilitation centres in the Kumasi metropolis face financial hardship. This not only hampers the quality of service delivery and the day-to-day running of activities, but also affects the quality and quantity of meals served to trainees. Trainers/administrators sometimes resort to borrowing money in order to cope with the situation.

".....Yes.... As for financial challenges, we face them. For example, in the vocational department, there are times due to the absence or unavailability of materials needed for the work, that we are not able to deliver our services due to financial constraints. So the students come and they are not able to learn the vocations they are expected to be learning. So, there is this constraint, financial constraint. And when it is like that, we begin to teach them only the theoretical aspect of it, but they are not able to get the practical aspect" (Participant GC1).

“...Financial challenges do affect us. It affects our planned menu. Because of inadequate funds, we cannot follow our menu. We begin to eat what we have and no longer follow the menu. If we are supposed to be eating porridge in the morning, rice in the afternoon, and banku (a local food prepared with corn) in the evening, at times we eat rice three times daily, because it is what we have at that moment. It also affects the quantity of food we serve; we have to be sure that everyone gets something to eat” (Participant D5).

“...We manage. As a manager of the school, you must go and purchase items on a credit base and if that happens, you pay a higher price than the actual price. Now some market women are reluctant to give us the goods on credit. Sometimes we have to use our own money or raise money (loans) in our name to cater for the feeding of the students and later on when the funds are released, then we redeem it” (Participant D3).

Infrastructure and Facility Challenges

All the training centres mentioned lack of space and decrepit facilities, including classrooms and dormitories for both sexes. Consequently, students were admitted on a ‘first come, first served’ basis, and there was a long waiting list.

“...Everything of ours is old, everything is in shambles. As for infrastructure, we don’t have a good infrastructure. The roofs are leaking; the window nets are torn. Some of the doors are not even good. So many things are not in proper shape” (Participant EC2).

“...Facilities need expansion because in Ghana, the teacher-child ratio is one-is-to-eight [for special schools]. And with this ratio, because of the increasing rate of pupils with intellectual disability in our system these days, here we are taking one-is-to-thirteen, fourteen and even sometimes fifteen. Meanwhile, these classrooms that were built for eight students are now taking double than normal. And even with this, there are a good number of students who are on the waiting list to be admitted to the school. So, we have challenges with infrastructure” (Participant GC4).

Human Resource Challenges

The study found that although the majority of the staff had higher qualifications, few were special needs educators. Staff members might be expected to have a sound background in technical and vocational areas, but most vocational

departments seem to lack tutors with the requisite technical and vocational skills.

"...We are adequately staffed. All the classes have got teachers and trained teachers. Most of them are degree holders and diploma as well. Except for a few who have a diploma, most of us have at least first degree, some have second degrees, they are not many though, but everybody qualifies" (Participant GC1).

"...Staff adequacy, what happens is that if you are teaching students with special needs, the teacher and the staff must also be trained professionally. When you come to our institutions, certain classes don't have special educators, people who are trained to manage students with special needs. This is because we don't have adequate special educators so I will say we don't have adequate teachers. No motivation so they come and go" (Participant ED1).

"... Like the vocational department, it is structured in such a way that we have carpentry, life skills, and leatherwork but we don't have the requisite staff to handle. We need some people from outside, maybe skilled carpenters to come to the school and teach the students as teaching assistants alongside the regular classroom teachers. So, if we get those assistants, it will help" (Participant GC2).

Personal Challenges

The study revealed trainer-specific challenges which tend to influence service delivery and commitment levels. Most teachers are stigmatised and called derogatory names because of their work with students with disabilities. Another issue is the lack of motivation among the staff.

"Oh yeah! For stigma it is true. We do face them. Some people even think that we are posted here because we are academically poor. And then also, sometimes if we go for workshops and whenever you mention Garden City Special School, people make comments like "Ayarifo School" (school for the sick). It is because the perception of the people out there is different from the book. They think that we are sick. It is just a condition. At times too, people see us in town, and they are like: "Ayarifo teachers" (teachers for the sick), look at all these" (Participant GC5).

The participants' responses made it clear that this did not have a negative influence on their work. They attributed their attitude to the knowledge acquired through their education, which the general public is not privy to, and their passion for the

work.

“...it is my work and whatever you say it is, that is what has made me whoever I am. So, I care little about that. I see myself contributing to society” (Participant D2).

“...This stigma has not affected my work output and has not brought down my morale since I have not allowed this to overpower me” (Participant EC2).

A major challenge that the participants reported was the distance they had to travel from their area of residence to their workplace. There were no facilities to accommodate them on campus. They felt that travelling to and fro affected their performance at work.

“...I think my distance bothers on my teaching, I come from Offinso which is a faraway distance from this school. I board a car every day to come here because my family is there, and I can't live here without them. So personally, that is the challenge I'm facing in this school. Besides that, nothing” (Participant ED3).

“...Where I live, and my place of work is very far. Because this school is closer to the university the cost of the apartment around here is very expensive. So that is very challenging. Where I live, my transportation costs each week alone are more than GHc 60.00. I have to pick up three different cars before I reach here. I have to wake up very early before 5:00 am every day to be able to reach here around 7:30 am” (Participant D1).

Proposed Interventions for Effective Delivery of Vocational Rehabilitation

The researchers elicited the views of participants regarding the best way to ensure effective delivery of vocational rehabilitation in the metropolis. Most of the participants were of the opinion that steps should be taken towards improving staff motivation, making prompt payment of grants, providing teaching and learning materials, and improving the infrastructure.

“...I think in this institution as an institution for people with intellectual disabilities and all institutions for persons with disabilities, the teachers ought to be motivated. Yes, motivation is a very serious issue; if it is done, the teachers will feel happy being here. Trainers come and they easily want to go, all because they are not well motivated” (Participant GC2).

“...The government should pay attention to special schools. Because we need more help. If not, a time will come when people may not be willing to be posted here. Teachers come and they don't have teaching and learning materials to impart what they have been taught. For instance, all my machines have broken down and the headmaster's own that he brought from home is also spoilt. So, when I come, I have to sit idle” (Participant D1).

“...I think adequate teaching and learning materials and improvement in infrastructure. And then also, more human resources who are special educators with skills in vocational and technical aspects should be posted here” (Participant GC5).

DISCUSSION

Globally, many organisations have acknowledged and praised the positive impact of vocational rehabilitation. For example, the 2013 report of the British Society for Rehabilitation Medicine indicated that vocational rehabilitation has enabled persons with disabilities to gain access, return to, and have the ability to remain in employment. However, vocational rehabilitation in the Kumasi metropolis has not received the necessary attention and support from the government, even though the Disability Act makes provision for persons with disabilities to receive vocational training.

Analysis of the data revealed that centres for vocational rehabilitation have not been given adequate administrative grants and goods and services grants for about 6 years. The only grant given by the government was released after a lot of delay. Such delays in the release of funds tend to affect the successful running of the centres. The view of Straaton, Harvey and Maisiak (1992) that government support and commitment to vocational rehabilitation programmes are inadequate corroborates this finding. Inadequate infrastructure was seen to have inhibited the effective delivery of vocational rehabilitation in the Kumasi metropolis. Classrooms meant to accommodate 8 students with a disability now accommodate three times that number. Learners do not benefit from quality training since tutors have neither the skills nor the time to attend to individual needs. The teachers are burdened with extra work and this adds to the difficulties. It was observed by Hawley (2011) that “shortage of classrooms or old infrastructure and limited space also makes it difficult for the implementation of vocational rehabilitation programmes”.

When admissions are offered on a 'first come, first served' basis, as seen in this study, most students with a disability, especially those from rural areas, could remain uneducated because parents may give up trying for admission in vocational rehabilitation institutions. This finding is in agreement with a report by the Ministry of Education (2013) that there seems to be a reduction in the number of students enrolled in special schools in Ghana. For example, enrolment during the 2006/7 academic year was 6,432 pupils but it was reduced to 5,560 at the end of the 2012/13 academic year (Ministry of Education, 2013).

Ngobeni (2015) observed that the absence of teaching and learning materials is a great obstacle that subsequently affects the success of vocational rehabilitation. The current study also revealed that the lack of teaching and learning materials could be an obstacle to the success of vocational rehabilitation programmes in the metropolis. Inadequate training materials in vocational rehabilitation imply that students with disability may not acquire skills needed in the labour market (Opoku, 2016). This confirms the assertion by Gadagbui (2008) that vocational training is not always beneficial to students with disabilities as they do not acquire the training needed to establish their own businesses and become independent.

The present study found that staff adequacy was fairly good, although a little inadequacy was noticed in respect of non-teaching staff. Most of the staff were qualified teachers employed under the Ghana Education Service. This finding contradicts Ndala (2006) who opined that in sub-Saharan Africa only slightly more than 50% of special schoolteachers have the proper qualifications, which is insufficient for achieving quality education for students with special needs. The issue however is the fact that most of the tutors had special education qualifications but had additionally not been trained to impart vocational training. This finding is congruent with that of Howard (2009) who argued that a lack of qualified specialised trainers to carry out vocational rehabilitation programmes is one of the major barriers confronting vocational rehabilitation centres. Ngobeni (2015) also made a similar observation, asserting that tutors responsible for vocational rehabilitation programmes sometimes experience difficulties since they are not trained to offer these programmes.

Other factors revealed in this study that have the potential to affect the success of vocational rehabilitation in the metropolis are: long-distance travel from teachers' residences to school, stigma and the use of derogatory language against teachers because of their association with students with disabilities. However, stigma was not seen to have had any effect on delivery of vocational rehabilitation. This finding, however, contradicts that of Chaula (2014) who reported that most of the

teachers who train students with special needs show negative attitudes towards their students. One important aspect revealed by the current study pertains to teachers'/trainers' motivation. Hayes (2011) stated that sufficient motivation is necessary in every area of life because it has a strong role in igniting interest and commitment to participate in and work towards achieving the desired results. Due to lack of motivation, most tutors take on an extra job as a substitute so as to earn additional income. This finding confirms Ngobeni's (2015) report, that there is insufficient support and motivation among management and educational trainers in vocational rehabilitation centres for effective delivery of services.

Measures that need to be put in place for the effective delivery of vocational rehabilitation are in line with suggestions put forward by the UNESCO (2011). According to UNESCO, institutions designated as special schools should be adequately equipped with suitable support services and resources and should employ customised instructional programmes that will address the needs of students with disabilities. If this is ensured, tutors will be able to deliver on the mandate and enough attention would be paid to individual needs, to the benefit of all. Chaula (2014) recommends that there should be adequate provision of teaching and learning materials which are helpful for teachers to train learners with special educational/vocational needs. Vocational rehabilitation cannot achieve its goals to the fullest if the facilities and infrastructure are inadequate for teachers to perform their duties in instructing students with disabilities.

Limitations

This study focused on the views of the staff who work directly with students with disabilities in the various vocational rehabilitation settings in the Kumasi metropolis. The views of students with disabilities and their parents are not included. This is a limitation of the study. It is believed that the study participants, rather than the parents, were in a better position to provide the necessary information. Moreover, it could have been difficult to trace all the parents, as students at the vocational rehabilitation centres come to Kumasi from different parts of the country.

CONCLUSION

Effective collaboration between government ministries and non-governmental organisations is vital to ensure that the needs of vocational rehabilitation centres are met. Reliance solely on government support means that in most cases these

centres cannot function optimally. Currently government support is inadequate in comparison to similar activities done by non-governmental organisations such as religious bodies.

The government, through the Ministry of Education, should reinstate the goods and services grant and administrative grants, and minimise delays associated with the release of these funds to the vocational rehabilitation centres. This would contribute to their efficient running.

Again, through the Ghana Education Trust Fund, the government should build enough classrooms, dormitories, and teachers' bungalows. Proper accommodation on campus for (most of) the staff members will contribute towards improving their work. Furthermore, there is a need to increase the capacity of vocational training centres to admit more students and thereby do away with the long waiting list for admission.

The Ghana Education Service should ensure that special education teachers with strong technical and vocational backgrounds are posted to these vocational rehabilitation centres. The trainees will then stand a better chance of acquiring marketable vocational skills.

The National Commission for Civic Education should enlighten the general public about disability issues since the persistent gap in knowledge about disability results in stigma and discrimination.

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Employment Needs of Young Adults with Visual Disability need to be Recognised in Kabul, Afghanistan

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ABSTRACT

Purpose: *The aim of this qualitative paper was to understand the employment needs of young adults with visual disability in Kabul, Afghanistan.*

Method: *The phenomenological approach was employed to obtain rich data based on the participants' personal experiences. In-depth semi-structured interviews were conducted with 14 adults with visual disability, between 20-40 years of age, using open-ended questions to shed light on the employment needs of this population. The data derived from the interviews was transcribed, translated, and thematic analysis was performed.*

Results: *Findings indicate that people with visual disability need to be equipped with essential skills to be competent workers. Support from employers and society is needed and, importantly, encouragement from family members and those involved in advocacy of the people with visual disabilities.*

Conclusion: *Improving the public's awareness regarding personal and vocational abilities of people with visual disabilities, enhancing the skills necessary for employment, promoting their abilities, family support and maintaining positive attitudes are some of the strategies which could result in better employment prospects for people with visual disabilities in Afghanistan.*

Key words: *young adults, visual disability, employment needs, Kabul city*

INTRODUCTION

Afghanistan is a landlocked country where war has been an ongoing phenomenon for over four decades. Consequently, many Afghans are living in poverty and enduring inadequate health services, education facilities, and poor

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job opportunities. This is affecting their intellectual and psychological well-being (Cardozo et al., 2004). A recently published survey noted that Afghanistan's poverty rate has compounded tremendously in the last five years as the economy has slowed down. More than half of the population is living on less than a dollar per day (Reuters, 2018).

Decades of conflict have led to widespread human suffering, ranging from psychiatric disorders to depression, anxiety and stress (Murthy & Lakshmi Narayana, 2006). People's health has been affected, both physically and psychologically. The cases of firearms or mine incidents, rape, permanent disability, diseases, forced migration, underage soldiers, lack of education, loss of family members, torture, and socio-cultural changes are on the rise (Çelik& Özpınar, 2017).

War has been the cause of many disabilities in Afghanistan. It is estimated that 3.7% of the Afghan population (over 850,000 people) has a form of disability (UNICEF, 2013). According to the World Health Organisation (2008), there are about 400,000 people with at least one visual disability in Afghanistan and 1,500,000 people with visual impairment. In addition, Afghanistan's Ministry of Public Health estimated that there were about 20,000-25,000 people with visual disability (The British Broadcasting Corporation, 2019). Specifically, 2% of the whole population of the country has visual disability or impairment (The British Broadcasting Corporation, 2019).

Main Contention

People with visual disability have minimal job opportunities in Afghanistan. The Law of Rights and Privileges of the Disabled (2011), in line with Article 22 of the Afghan Constitution, demands that the government should hire at least 3% of eligible people with disabilities. Ali Eftekhari, the spokesman for the Ministry of Labour, Social Affairs, Martyrs and Disabled, indicated that unfortunately, despite the repeated emphasis, this Article of the Law has not been implemented (Pajhwok, 2014). Some legitimate obstacles, along with the negative mentality of people in society, are the main causes which impede the employment of people with disabilities and the achievement of their rights (Community Centre for the Disabled, 2014).

In addition, people with visual disabilities are continuously fighting against all forms of discrimination. Referring to the Fundamental Rights and Duties of

Citizens, Article 22 of Chapter 2 of the Constitution (AFG. Const. Art. 22, Chap 2, 2004) indicates that any kind of discrimination and distinction between citizens of Afghanistan shall be forbidden. However, the rights of people with disabilities have been denied in various spheres of life: social, economic, political, cultural, educational, recreational, and sports (Article 15, Law of Rights and Privileges of the Disabled, 2011). Soraya Paykan, Deputy of the Ministry of Labour, Social Affairs, Martyrs and Disabled, revealed the fact that the work done by the government and international organisations to improve the status of people with disability is not adequate in Afghanistan until now (The Killid Group, 2014).

Generally, persons with a disability are more disadvantaged and face greater challenges than other people. Apart from their physical, intellectual or sensorial impairments, they encounter prejudice, discrimination, stigmatisation, inequalities, isolation, and disrespect from the community at large (Trani et al., 2005). The consequences of these attitudes are evident. For instance, only 20% of children and youngsters with disabilities have access to educational services (Pajhwak, 2012). Lack of proper education affects their financial capability in leading independent lives and in seamless assimilation in society (Furlong, 2009). Education plays a big role in the development of not only economic, social and moral values, beliefs, and ideas, but also in providing future opportunities and direction (Farah et al., 2014). As the next step, employment for young adults is crucial for their development as well as the development of society.

Some Important Issues

a) Lack of Data

There is no statistical data available on the employment needs of people with visual disability in Afghanistan, although there is sufficient data available about the employment of people with disability from other low- and middle-income countries. The World Health Organisation's World Report on Disability (2011) provides information about services needed for the employment of people with disability. According to the report, in Namibia 47.3 % of people with disability need vocational training and other services to be employed, but only 5.2% receive such training and related services. Similarly, in Zimbabwe, 41.1% of people with disabilities need vocational services but only 22.7% receive them. In Malawi, 45.0% need vocational services but only 5.6% receive them, and in Zambia, 35.1% need vocational services whereas only 8.4% receive them (WHO, 2011). While relevant

information on the employment and vocations of persons with disabilities is available from several countries, in many cases it is not systematically gathered or reported. The International Labour Organisation's (ILO) survey of 2003 shows that only 16 out of 111 countries had data regarding employment of people with disabilities (Lepper, 2007). Despite recent improvements in low- and middle-income countries, the limitation of available data continues (WHO, 2011; Benshoff, Barrera, & Heymann, 2014). However, the data indicates that employment rates of people with disabilities are always lower than employment rates of the overall population.

One of the major concerns regarding people with visual disability is their low employment rates anywhere in the world (McNeil, 1997). Employment is important for people with visual disability because it affects their financial capability and independent living.

b) Current Status of Employment and Unemployment

A successful economic status contributes to the integration and inclusion of individuals in society (Furlong, 2009). One of the factors that seem to impact employment outcomes is the level of education. Higher and better employment outcomes are associated with educational attainment. Hence, it is the well-educated or trained individuals who are employed and who have prospects for better incomes (Bell & Mino, 2013). People with disability are employed in administrative, executive and managerial jobs. Job opportunities are available for them in technical, marketing and sales domains, including clerical service, precision production, crafts and reparation, agriculture, forestry, fishing, and related jobs (Wolffe & Spungin, 2002).

In an advanced country like the United Kingdom, a high proportion of persons with loss of sight are unemployed due to lack of proper training. Another reason for unemployment is the considerable discrimination which they face in the labour market (SSMR, 2009).

In spite of reportedly better performance at work, there are fewer employment opportunities for people with disabilities and most of them are jobless. Several researchers have identified numerous barriers to employment and suggested strategies to remedy those barriers (Crudden & McBroom, 1999). Barriers that have been identified are: difficulty with transportation (Rumrill, Schuyler & Longden, 1997; Samuel et al, 2013; Crudden et al, 2015; Cmar et al, 2018); history

of illness; and discrimination of women and those with low levels of education (Wehbi & El, 2007; Harrabi, Aubin, Zunzunegui, Haddad & Freeman 2014). Other barriers include a lack of general awareness about visual impairments or the attitudes of the public and employers towards people who are blind (McBroom, 1995; McDonnall, O'Mally & Crudden, 2014). Inadequate funding for adaptive equipment and lack of assistive technology (Malakpa, 1994), and the absence of role models (Young, 1994) are also barriers according to some other studies (Wehbi & El, 2007).

Wehbi and El (2007) reported a range of issues which affect access to employment by people with disabilities: a lack of personal connections, discrimination, lack of available employment opportunities, transportation difficulties, family pressure not to be employed, and inadequate education or vocational training. Inadequate legislative support is another barrier listed by Wolffe and Spungin (2002) and Wehbi and El (2007). The major impediment towards the employment of persons with visual disability is the limited awareness of the public regarding their physical and mental capabilities. Unemployment among people with visual disability is still a problem and has not been resolved as yet (SSMR, 2009; Kelly, 2013; American Foundation for the Blind - AFB, 2015; Silverman, Mendez, & Bell, 2019).

c) Measures for Improving Job Opportunities

It is believed that one of the most difficult jobs of governments is to ensure reasonable accommodation for people with visual disabilities and remove the existing barriers (Butler et al, 2002). Some researchers have argued that the governments should improve public awareness regarding personal and vocational needs of people with visual disability, enhancing the opportunities for employment, promoting family support and maintaining a positive attitude towards people with disabilities (Salomone & Paige, 1984; Wolffe, Roessler & Schriener 1992; Young, 1994).

Employers need to be equipped with knowledge on how to adapt themselves and the workplace to the needs of people with disabilities. This support is necessary to ensure that people with disabilities have equal opportunities like their fellow workers without disability. In line with this, facilities for social interaction and interpersonal communication should be improved within companies that employ those with visual disability. Furthermore, the inability of the person with visual disability to communicate with others non-verbally needs to be recognised by all

employees to guarantee better social interaction. As a result, employees with a visual disability will be regarded as being employable (Naraine & Lindsay, 2011).

Companies which employ people with disabilities must be targeted for advocacy purposes as they can serve as an example – a role model – to others (Bell & Silverman, 2018).

Cimarolli and Wang (2006) argue that compared to unemployed people with visual disability, people with visual disability who are employed feel overprotected by people around them. By failing to fulfil the needs of citizens with visual disabilities and failing to help them integrate into the workforce, a great deal of labour productivity would be lost (Harrabi et al., 2014). The key issue for adults with visual disability is the level of support which they need, receive and demand in leading a 'normal' life.

Jezari (2012), in a study done in Uganda, concluded that people with disabilities should get suitable education. He identified two areas that need to be improved, namely, good education and proper support from and within society. People with visual disability must be supported by their family, government and civil society. Lack of social support will act as a barrier to accessing education, being integrated into society, and ultimately to finding employment (Gold & Simson, 2005; Jezari, 2012). Facilities at workplaces for people with visual disability need to be improved and, for instance, should include proper access to restaurants i.e., such facilities should be accessible without difficulty and assistance from colleagues (Naraine & Lindsay, 2011).

Finding most of the earlier publications outdated, quantitative in nature and not relevant to the current situation, the authors of the present study concluded that there is a need for new qualitative studies on the employment of people with visual disabilities living in low- and middle-income countries. They identified areas which deserved further research and analysis, especially regarding the employment needs of young people with visual disability in Kabul city.

Objective

This qualitative study about the employment needs of people with visual disabilities living in Kabul city aimed to gain insights into the experiences of young adults with visual disability on their journey towards employment.

METHOD

Study Design

A qualitative approach was adopted. In particular, a phenomenological approach was selected and adopted for examining participants' life experiences (Donalek, 2004). As a part of this study the researcher spent some time with the study respondents. Phenomenology helped the researcher to explore and understand encounters and experiences without any pre-assumptions of those encounters and experiences (Converse, 2012).

Participants

The respondents were selected based on the characteristics and objectives of the study. The study sample purposefully consisted of young adults with visual disability living in Kabul – in order to study the right and “information-rich” cases (Palinkas et al, 2015). There were totally 14 participants in this study (7 males and 7 females). All of them were adults, aged between 20 and 40 years, with a mean age of 30 years. Table 1 shows the demographic information of the study population.

Table 1: Demographic Information of the Participants

Name	Age	Gender	Education	Major	Job	Marital Status
P1	39	Female	Bachelor's	English	Teacher	Married
P2	31	Female	Bachelor's	Special Education	Teacher	Single
P3	33	Female	Double Master's	1. Law and Political Science 2. International Relations	Commissioner of Human Rights	Married
P4	40	Female	General college	English Literature	Teacher	Married
P5	30	Female	Bachelor's	Law	Prosecutor	Single
P6	29	Female	Bachelor's	Special Education	Jobless	Single
P7	25	Female	Bachelor's	Literature	Jobless	Single
P8	27	Male	Master's	Commentary and Hadith (Tafsir and Hadith)	Teacher	Married
P9	40	Male	Bachelor's	Education	Owner of NGO	Married

P10	34	Male	Bachelor's	Literature (Dari)	Presenter of radio programmes	Married
P11	40	Male	Bachelor's		Teacher (online teaching)	Married
P12	32	Male	Bachelor's	Special Education	Teacher	Married
P13	29	Male	Bachelor's	Special Education	Jobless	Married
P14	40	Male	Double Bachelor's	Education Sharia	Head of Islamic Education department in a special school Owner of Alfalah Madrasa	Married

Data Collection

A semi-structured interview was designed, to obtain subjective responses from participants about a particular situation or phenomenon they had experienced. Interviews continued until the point of data saturation was reached and no new information was given.

The interview guide consisted of two parts. The first part contained demographic information such as name, age, gender, educational background, type of job, marital status, and type of disability (congenital or acquired before the age of 5 years). The second part was designed to address the employment needs of the participant; this part had a total of six main questions.

The data collection procedure was done in two phases - the pilot interview and the actual interview. The pilot interview was followed by the actual interviews during which open-ended questions were used to generate data from the participants. The sessions were recorded with the participants' permission. A consent form was obtained from the participants prior to the interview sessions. The interviews were conducted in two Afghan national languages - Pashto and Dari.

Data Analysis

Thematic analysis was applied to analyse the data and the six-step procedure was followed as suggested by Creswell (2016).

Ethical Considerations

Priority was given to ethical issues such as informed consent, confidentiality and anonymity, and protection of the study subjects.

RESULTS

The objective of this study was to gain insights into the experiences of people with visual disability regarding their employment journey. Three themes and five sub-themes were identified as employment needs.

Equipping with Essential Skills to be Competent Workers

People with visual disabilities need certain skills to participate fully in daily life activities, whether at home or at the workplace. The first theme that emerged was the necessity for people with visual disability to be equipped with essential skills to be competent workers. Most of the participants mentioned skills that a person with visual disability must have in order to be hired and to be competent in the labour market. This will be elaborated on under the two sub-themes: professional skills and life skills.

Professional and Vocational Skills

Participants reported that professional skills are essential for successful career development. The professional skills mentioned were: adaptability and flexibility; ability to speak several languages - especially an international language; persuasiveness - such as the ability to convince an employer during a job interview; digital literacy skills; and, communication skills. Regarding vocational skills, the interviewees gave the example of weaving. Most of the participants mentioned the importance of being equipped with vocational skills that meet the requirements of employers so that they face fewer difficulties in doing their jobs well.

“I know that I can do any job. The only thing I need is to have some skills, which mostly I have. I have a bachelor’s degree. I have skills in computers, I can speak the formal languages of my country and English too I can speak” (P2).

“We must be fully skilled in the required fields as an employee. I need to be skilled in technology, I must be flexible in my job place and as a blind person, I have to adapt to the environment. Otherwise, those who are hiring us, why not hire a person who has normal sight and who can work normally” (P11).

“In order to compensate for the absence of our vision, we need to be fully skilled in technology, communication, and time management. We must be creative so we can work effectively and do our job successfully” (P9).

Life Skills

The importance of possessing the necessary skills to obtain and succeed at a job was confirmed by approximately three-fifths of the participants. However, they referred to the need for life skills as well, e.g., coping well with one's disabilities, having problem-solving skills, and possessing some creativity.

“First of all, we must have the skill and ability to cope well with our disability. We have to accept our disability, and we have to recognise our abilities so there is when we can do any job with more confidence. Secondly, we must be skilled in communication in order to convince the employer and then continue our job. Being skilled in communication is much needed for people with visual disability because this is the best way for us to show the ability we have. Third, we must be skilled in working with computers, using smartphones and other necessary technology creatively. Last but not the least, we must be adaptable and flexible in the field where we work in order to not differentiate from other workers” (P3).

Thus, participants believed that having the afore-mentioned skills would make it easy for people with visual disability to get and successfully retain their desired jobs.

Support from Employer and Society

According to the participants, while the people with visual disabilities have to qualify or make themselves suitable for a job, the employer also has certain responsibilities when hiring. In this context there are two sub-themes that require attention: 1) creating opportunities for people with visual disability, and 2) raising community awareness about the abilities of people with visual disabilities.

Creating Opportunities for People with Visual Disability by the Employers

The findings revealed that there is not very much difference in the abilities of people with and without visual disabilities. The participants felt that the factors that could contribute towards more work opportunities for people with visual disabilities were: employment prospects; creating more jobs, internship or placement opportunities; job training; the availability of transport, accommodations and financial resources.

“The government needs to provide more employment opportunities and vacancies for us. The more we have job opportunities, the more we will feel confident to apply. Because most of the time we apply but wherever we go there

is no single job for us” (P13).

“We can do our job as others can do. We just need some equipment, conditions, and a barrier-free environment to perform our job well. Effective accommodations allow persons with disabilities to perform their duties to the best of their abilities. It is important to have the right accommodations in our workplace so we can participate as valued members of the working team” (P9).

Another participant suggested that opportunities for employment might not be available because employers think that the tools needed by people with visual disabilities are expensive.

“I am not asking for costly tools or special treatment, but some simple steps which pave the way for creating equal access to be equal contributors in my job. We request often little cost accommodations or sometimes even no cost is needed to be paid and can highly impact our success in the job” (P10).

For some participants, the working environment was very important. One of the participants who worked in a governmental organisation valued the environment a lot.

“Most of the time, the environment is not prepared for the acceptance of persons with visual disability to be integrated into many organisations as employees” (P5).

A participant who was a teacher was concerned about other people with visual disability.

“We need to work; if we do not work then we have to beg, which is something really shameful in our culture. Our government must consider some specific training and instruments so we can do anything. I was weaving jackets besides teaching. During the Taliban regime when women were not allowed to work, I was knitting jackets at home and selling them. And there was an NGO which gave us 7kg of flour substitute for one jacket. I got even a prize for knitting the best jackets. But now I am not weaving anymore because of the Chinese goods which are very cheap. My husband was killed, and I have to take care of my children too with my salary” (P1).

Raising Community Awareness about Abilities of People with Visual Disabilities

Participants mentioned that raising public awareness about the abilities of people with visual disabilities is as essential as creating awareness about their disabilities. In other words, the public must be aware of both their disabilities and abilities. The participants laid particular emphasis on the dissemination of information regarding the abilities of people with visual disabilities in the community and introducing successful employed people with visual disabilities as role models to the community and to the Ministry of Labour, Social Affairs, Martyrs and Disabled.

“Actually, they are not aware of employment laws and plans regarding people with disability. Otherwise, they will get ready to hire and work with us. Often employers are afraid of hiring us due to being unsure how we work and how they work with us” (P8).

“We must be placed in different posts according to our abilities, but unfortunately, due to not having enough knowledge regarding us, they just focus on our disability and forget about our abilities as human beings. Therefore, mostly the employer denies hiring us” (P6).

“I want to tell those who are not aware of our abilities and disabilities. Our differences with them are just at the level of being able to see and not being able to see. We are similar in the abilities; there are certain things that we cannot see but once we learn about it or if it’s tangible things or doable, we can do it except if it’s only to do with the sight” (P4).

“Our employers and colleagues may feel uncomfortable while working with us because they are not aware of blindness, or they do not understand what we need. They cannot be blamed because they never had the experience of working with us” (P11).

Some of the participants were emphatic about their own awareness regarding their responsibilities, abilities, and disabilities.

“We need to be aware and accept our responsibilities as an employee and our employer must provide services and facilities to remove the barriers which are impeding us to be fully participating and integrating with workload” (P3).

In conclusion, support from employers and society has been counted as one of the important initiatives in enabling employment for people with visual disabilities. Most of the participants laid emphasis on raising community awareness about the abilities of people with visual disability and on creating opportunities for hiring this population.

Encouragement and Support from Family Members and those involved in Advocacy of People with Visual Disabilities

Another vital theme that emerged from the interviews was that as employees, people with visual disabilities needed encouragement and support from their families and all those who played a role in advocating for their access to employment. They valued the support they received from teachers, non-governmental organisations, their families, and social support in general. They mentioned the role and importance of family support and encouragement to them.

“Wherever I apply for a job, and I could not get the job, my brother was telling me ‘this place was not made for you because you have more abilities than this job’. Sometimes he was giving me the example of other people who even were sighted but they were jobless, then I realised yeah, he is right I will get the job once it’s made for me. Next time I would apply with more confidence and more morals” (P11).

Another participant shared an interesting story of family encouragement and emotional support.

“My mother was my big inspiration. She was very much concerned about me. I guess she is still but now when I have my job, she says she is satisfied with my side, but I can understand she is still concerned about me. When I was a child, she heard from someone on the bus that there is a school where students with visual disabilities can study. When she came home, she was so excited. She took me there the next day. She was always telling me ‘I want to see the day when you graduate from school’. When I reached the end of my school she added on her demands and then she was expecting me to study my bachelor’s. She was the one who was reminding me about my abilities. I was not expecting myself to finish school even, but my mother kept telling me ‘when you can go to school and can study there, why not a university?’. And then, when I was in university, she was telling me ‘Once you get the job, that will be the biggest day of my life to see you independent’” (P2).

Teachers' support was also mentioned by several participants. In fact, they considered teachers as the most meaningful people in helping them achieve their aspirations.

"I will say there were some teachers who behaved the way that I was feeling I am the most incapable person in the world. One of my teachers would always talk to me and he was telling me 'you have to try more than other students, you have to show others that you have the abilities that they don't have, so they will only think what you can do and how you can do instead of what you can't do and why you cannot do'. I always pray for him. This was his support and encouragement that I am working now in such a place where even people with normal sight dream about to work" (P5).

It was inferred that while support from family and teachers is largely emotional and indirect, it however plays a vital role in terms of giving confidence to apply for a job or to carry on at the job successfully. Non-governmental organisations however, always had a tangible and direct effect on their employment and placement.

"I got all my training from NGOs. They taught me Braille, provided me teachers, and trained me in mobility and orientation. Shortly, whatever I am today, the NGO has played a huge role in my success. They even provided the opportunity of my admission to a school near my home. Otherwise, we were never aware of the fact that visually disabled can study" (P13).

"All the skills I have, have been blessed by NGOs. Tools I needed, skills I needed, training and anything else was provided by the NGOs. I mentioned before, anything we need cannot be found in the bazaar. If the NGOs were not providing these all services, I don't know what would happen to me. Software and hardware for the computer, repair of the instruments we use for Braille writings, and even beyond them are given to us by them. A tape recorder, converting Braille, printing Braille, and any other service, all are provided by these few NGOs in Kabul city. I always appreciate their services and support they provide to the visually disabled" (P12).

This sub-theme shows that family, teachers, and non-governmental organisations play a significant role in encouraging people with visual disabilities to believe in their abilities. They support them to strive for jobs and provide them the essential skills, tools, and training.

DISCUSSION

Equipping with Essential Skills to be Competent Workers

There are few opportunities in the city of Kabul for people with visual disabilities to be hired as employees. A similar situation has been noted by the National Federation of the Blind (2010) in the United States of America. Obama (2010), Agran, Hughes, Thoma, and Scott (2016), Erickson, Lee, and von Schrader (2016), Preston (2018) and Silverman et al. (2019) also indicated that those who are blind are mostly from a disadvantaged socioeconomic background and this population is less likely to be employed. In addition, Pellerin (2010) in a study found that despite having fair reasons for employability and having legislation support such as the Americans with Disabilities Act, opportunities available to make use of employment services such as rehabilitation and vocational training, and a high level of accessibility to technology, people with visual disabilities still struggle to become part of the workforce and lack equal opportunities. Similarly, Benschhoff et al (2014) showed that in India employment rates of people with sight loss are way below the average employment rates.

The present study indicates that those with visual disabilities need to be equipped with essential skills to secure jobs. A number of skills are required to convince an employer to hire someone with a visual disability. Groh et al (2016) also had similar findings. They argued that while formal schooling provides people with visual disabilities some technical skills, to be a successful employee, other skills are needed too. These skills include social interaction skills, skills for working in a team, skills for reacting professionally, and especially personal presentation skills for job interviews.

Preston (2018) argued that to prepare people with visual disabilities for employment, the existing support programmes must be comprehensive. The Workforce Innovation and Opportunity Act or WIOA (2014) laid significant emphasis on the rehabilitation of adults with disabilities via the provision of services and training. Having adequate education and vocational training is very important for people with disabilities (Wehbi & El, 2007; Bell & Mino, 2013; Lindstrom et al., 2013). The skills needed to be a competent worker are categorised in the present study as professional and vocational skills, life skills, and soft skills. The government and employers in Afghanistan rarely provide training and workshops specially for people with disabilities to become skilled in certain areas of work. This study found that, despite the importance of life

skills needed for the employability of the youth, there are few such programmes available in the study region.

The present study supports the study by Naraine and Lindsay (2011) that lays great emphasis on enhancing communication skills of people with visual disabilities. Naraine and Lindsay (2011) recognised the communication difficulties which many people in this group have, as a failure for interacting socially. Therefore, Salomone and Paige (1984), Wolffe et al. (1992) and Young (1994), concluded that people with visual disabilities need to be equipped with essential communication skills to be competent employees.

Support from Employers and Society

The findings of this study showed that people with visual disabilities need support from employers and society to find jobs and perform them well.

Enhancement of the abilities of people with visual disabilities will contribute to increased employment rates for this group. The Ministry of Labour, Social Affairs, Martyrs and Disabled should be asked to consider the rights of people with visual disabilities to get jobs. In addition, those who are working successfully should be introduced to the community as role models. Crudden and McBroom (1999) explained that role models are significant factors in creating and maintaining motivation of people to get a job. Crudden and McBroom further explained that role models do not only serve as examples to people with visual disabilities but also can provide information on employment opportunities. Rehabilitation providers must be in contact with role models to generate and develop support systems for others with visual disabilities. Support systems could be valuable for those who may receive limited family support.

Baril (2013) and Bell (2010) also showed that the use of mentors and role models play a significant role in improving self-esteem. Some of the earlier studies (Salomone & Paige, 1984; Wolffe et al., 1992; Young, 1994) have shown that improving the public's awareness regarding personal and vocational abilities of people with visual disabilities and making use of role models are ways to overcome the barriers preventing the employment of people with visual disabilities.

Raising awareness, especially among the employers, is very important. This finding is in support of the Bell (2010) and Silverman (2018) studies. Bell and Silverman demonstrate in their respective studies that employers must know how to adapt themselves to employees with visual disabilities to ensure that they receive the

same support as their other co-workers. McDonnall, Zhou, and Crudden (2013) and McDonnall (2014) demonstrated that employers' negative attitudes form a major barrier for the employment of people with visual disabilities. Therefore, the aforementioned authors emphasise the importance of educating employers about the abilities of people with visual disabilities.

Mishra (2019) recommended implementing Total Quality Management (TQM) within the organisation (a concept which was developed by Shewhart in 1920). TQM gives importance to encompassing respect for each and every employee, considering everyone equal with latitude, flexibility, and innovative interaction. This includes creating and providing working opportunities for people with disabilities and others who also are at risk of losing their work in the labour market for various reasons. TQM also assists organisations to create a friendly working environment, with freedom to exchange opinions and ideas. In addition, the SSMR survey (2009) in the United Kingdom states that there is less awareness among employers particularly about employees with visual disabilities, even if their sight loss does not affect their working abilities. Informants of this survey believed that the main reasons for unemployment of people with disabilities are discrimination of employers, based on ignorance and fear.

Most of the participants in the present study reported that they got their jobs through mediators. The mediator is a broker who hires the person with visual disability (legally or illegally) because of a personal relationship, a bribe, or for being the relative of the employer himself. The study participants asserted that the mediator plays a significant role which cannot be ignored. It is of vital importance for people with visual disabilities to get a suitable job in Kabul city. Some of the participants are still jobless because they do not have any mediator in governmental institutions. There is no documented empirical research to support this finding. Contrary to this, the mediator has been mentioned in other studies as counsellor and advisor in choosing a profession, finding and maintaining a job, and mending disputes in several aspects of working life (Mishra, 2019). However, in line with the previous studies, it can be concluded that people with visual disabilities are in need of support from employers and society.

Encouragement and Support from Family Members and those Involved in Advocacy of People with Visual Disability

Encouragement and support from family members and those involved in advocacy of people with visual disabilities were identified as significant and

important. This finding is consistent with the research conducted by Crudden, and McBroom (1999) and Pellerin (2010), which showed that family members and partners are important. They help to overcome the barriers of unemployment. In the study of Budiarti (2018), family support and social support were considered as the most influential factors for successful employment of those with visual disabilities. Emotional support for those with sight loss is very important (Jackson & Lawson, 1995; Bambara, 2008).

The support of family is essential when searching for a job and maintaining it. Encouragement, for example, in helping people with visual disabilities to apply for a job is significant. Besides, family support helps them to reach the workplace. This finding is in line with Crudden and McBroom (1999) who revealed that in addition to assistance with transportation, family encouragement and support increase motivation and confidence of people with visual disabilities, especially when the job search is not progressing well. Moreover, Bell and Mino (2013) explained that friends, peers, and social circles also extend their support along with support of the family. They also stated that positive support from the family can play a major role in the employment of people with visual disabilities.

Support from NGOs in Afghanistan is largely in the form of assistive devices and orientation and mobility training; nowadays this is limited because of the current political situation. It is worth noting that NGOs offer support largely in the domain of education but the participants in this study identified their support in the employment domain as well. The need for support from NGOs and those involved in the advocacy of people with disabilities is fully recognised by Ilieva (2006). Her study in Bulgaria highlighted three important roles of NGOs and stressed that those who are involved in the advocacy of people with disabilities should work on projects which really target their needs. The first role is that NGOs should contribute to the improvement of the educational level of people with disabilities and help them in finding jobs. The second role is to facilitate vocational training for people with disabilities. The third role is to empower people with disabilities by creating a communication platform and providing possibilities for adapted and accessible information.

From the findings of this research it can be understood that it is necessary for people with visual disabilities to get a job which is in line with their abilities. Encouragement and support from family members and NGOs have played an important role in their education. In addition, support from NGOs is needed for people with visual disabilities to get and maintain their jobs.

CONCLUSION

The current political and economic atmosphere in Afghanistan is responsible for the negligible employment of people with visual disabilities. In addition, their right to secure work has been seriously neglected in Kabul. It is important to highlight, in the context of this research, that the absence of national employment policies for people with visual disabilities have caused major setbacks to this community. Furthermore, they need to be equipped with the skills essential to be competent workers, and support is required from family members, employers, and society at large. In addition, creating opportunities for people with visual disabilities and raising community awareness regarding their abilities would increase their self-confidence, and pave the way for better employment opportunities.

Findings from the literature state that providing role models, improving the public's awareness regarding personal and vocational abilities of people with visual disabilities, enhancing the skills necessary for employment, promoting the abilities of people with visual disabilities, family support and maintaining a positive attitude are some of the strategies for overcoming employment barriers. Adopting these principles and strategies in Afghanistan could result in better employment prospects for people with visual disabilities.

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Efficacy of the Smartphone App for sending Text Reminders to reduce 'No Shows' in Speech Therapy Sessions at a Tertiary Care Centre in India

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ABSTRACT

Purpose: *There is a need for intensive therapy following cochlear implantation, but many clients fail to show up for their scheduled appointments at the therapy centres. This study aimed to establish the efficacy of a Smartphone app in reducing the 'no shows' among the population with cochlear implants (CI). A secondary aim was to find the level of satisfaction with automated reminder SMS messages among parents of children with CI.*

Method: *The study participants were 24 children with CI who were attending the Auditory Verbal Therapy sessions at a tertiary care centre. Half of them formed the study group and the other half the control group. Parents in the study group, with access to working mobile phones, received SMS text reminders about therapy and mapping sessions; parents in the control group did not receive any reminders. Data was analysed after 3 months, using a z-test for proportions to find the difference in the mean percentage of 'shows' in the study and control groups. A questionnaire was administered to the parents in order to evaluate their satisfaction with the SMS reminders.*

Results: *The number of 'shows' in the study group was 209 out of the scheduled 233 appointments, while the number of 'shows' in the control group was 173 out of the scheduled 232 appointments. The reminder system was effective for parents of children with cochlear implants to maintain appointment schedules with greater regularity as compared to the parents who did not receive the reminders.*

Conclusion: *SMS text reminders via a Smartphone app are a low-cost and effective method of reducing the 'no shows' in the Auditory Verbal Therapy and*

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mapping sessions for children with cochlear implants. Parents of the children in the study expressed a high level of satisfaction with the SMS text reminders. Future studies with a larger number of subjects could consider controlling the variables like income, education level, distance from the therapy centres and motivation of the parents.

Key words: *cochlear implants, auditory verbal therapy, Smartphone app, 'no shows'*

INTRODUCTION

When a client does not attend his/her scheduled appointments, it is called a 'no show'. The consequences of non-attendance include increased appointment waiting times (Gucciardi, 2008), increased costs of care delivery (Murdock, Rodgers, Lindsay & Tham, 2002; Weinger, Lin, McMurrich & Rodriguez, 2005), under-utilisation of equipment and personnel (Murdock et al., 2002) reduced appointment availability (Martin, Perfect & Mantle, 2005; Weinger et al., 2005), reduced client satisfaction (Taylor, Ellis, & Gallagher, 2002; Lloyd, Dillon & Hariharan, 2003), and negative relationships between clients and staff (Martin et al., 2005; Gucciardi, 2008). Although data on non-attendance varies, studies from around the world consistently report non-attendance rates between 15% and 30% in outpatient health clinics (Ulmer & Troxler, 2006; Taylor, Bottrell, Lawler & Benjamin, 2012).

Multiple studies that have investigated the reasons for non-attendance reported forgetfulness, competing work or family-related commitments, poor health, poor client-provider relationships, adverse clinical experiences, practice error, and client confusion over dates and times, as the most frequent causes of non-attendance (Martin et al., 2005; Neal, Hussain-Gambles, Allgar, Lawlor & Dempsey, 2005; Crosby et al., 2009). Some of these causes could potentially be averted - particularly practice error and client confusion over dates and times if a reminder service were implemented.

For children with severe to profound sensorineural hearing loss who will not benefit from hearing aids, cochlear implant surgery is a viable treatment option. Cochlear implant (CI) is a surgically implanted device that bypasses the outer and middle ear and directly stimulates the auditory neurons for the perception of sound. It has external (speech processor, transmitting coil, and cables) and internal (electrode array and receiving coil) components. After the CI surgery,

the external component (speech processor) is activated at an interval ranging between 3 - 5 weeks. This activation process is known as 'switch on'. The processor further needs to be programmed through a procedure called 'mapping'. During the mapping session, the stimulation levels of the CI's internal electrode array are adjusted so that the user can hear a wide range of sounds. Mapping needs to be done at regular intervals to enable the recipient to hear soft sounds as well as loud sounds at a comfortable level. For mapping sessions post 'switch on', the recipient is required to visit the clinician twice in the first month, then once a month for three months. Thereafter the visits should be once every three months, on two occasions, followed by visits after six months. However, the mapping schedule may vary depending upon the consistency of behavioural responses during mapping sessions. Recipients with consistent and reliable responses to the sound stimuli presented through CI have less frequent schedules for mapping sessions, whereas those with inconsistent responses during the sessions need to visit more frequently.

After 'switch on', the CI recipient undergoes regular speech and language therapy sessions known as Auditory Verbal Therapy (AVT). The intensity of rehabilitation and training in the auditory/oral method of communication are two critical variables associated with the successful use of CI (Buckler & Siebert, 1996). The frequency of therapy centre visits varies for each client, depending on the mapping schedule and frequency of speech therapy sessions. For an optimum outcome, at least two visits per week for AVT sessions (lasting 1 hour each) are desirable.

Benefits of Cochlear implants include improvement in auditory development, language growth, and improved speech intelligibility (Robbins, Koch, Osberger, Zimmerman-Phillips & Kishon-Rabin, 2004; Flipsen & Colvard, 2006; Kubo, Iwaki & Sasaki, 2008).). Apart from other factors such as the age at implantation, types of device used, communication mode, amount of time the device is worn, and chronological age (Geers & Moog, 1994), language acquisition of children with CI is also influenced by the nature and intensity of habilitation (Gates et al., 1995). A large number of children with hearing impairment from poor families receive a CI under the Assistance to Disabled Persons for Purchase/Fitting of Aids and Appliances (ADIP) scheme of the Ministry of Social Justice and Empowerment, Government of India. This scheme provides financial assistance for implants and surgery, as well as mapping and speech therapy post implant. Under this scheme, a therapy centre needs to provide mapping sessions in a fixed protocol, and speech therapy sessions thrice a week for two years after surgery.

As the 'no shows' cause the child to miss out on appropriate interventions and are a waste of time for therapists, it is imperative to employ an appointment reminder system. There are several client reminder systems including text messages on the mobile phone, postal communication, telephone call reminders, and email. However, postal communication is not feasible for the population with CI due to the frequency of visits required of them. Telephone call reminders are a good option; however, it may not be that easy to use in case of the clinician's busy schedule, lack of human resources to make phone calls to the clients, the inability of parents to accept a call at a particular time, etc. Email notifications do not seem to be an efficient way to remind parents about appointments as some of them may not make use of email services, may not check their email frequently, or may have internet connectivity issues.

The majority of the population worldwide has access to mobile phones. In January 2021, the total number of unique mobile users was estimated to be 5.22 billion, which is 66.6 % of the world population (Kemp, 2021). In India, mobile telephone penetration has been estimated to be the second-highest in the world, with 110.18 mobile connections per 100 citizens. By January 2021, about 85.53% of Indians had access to mobile phones (TRAI, 2021). One of the modes of communication through mobile phones is SMS text messaging. SMS text messages are a very helpful appointment reminder system. The efficacy of SMS text messaging in reducing 'no shows' is comparable to personal telephone calls (Car, Gurol-Urganci, de Jongh, Vodopivec-Jamsek & Atun, 2012). It is moreover a cheap method of sending information, is non-intrusive and more convenient than a traditional phone call. Nowadays, most mobile network companies provide free SMS services to their clients as part of their mobile plans, so text messages are virtually free in India. However, sending each client separate reminders can take up a lot of time for the clinician and can be very cumbersome to send several SMS messages manually. There are however a few android and iOS mobile apps available, which may be used to send SMS messages automatically.

Objective

As there is a need for intensive therapy following cochlear implantation, it seems a good idea to use an appointment reminder system to decrease the number of 'no shows'. Smartphone apps may be used to send SMS text reminders. This study aimed to find the efficacy of a Smartphone app that sends automated reminder SMS messages in reducing the 'no shows' among the population with cochlear

implants. It compared the attendance of the population with cochlear implants in a group that received text appointment reminders via a Smartphone app and in a group that did not receive any reminders.

A secondary aim was to find the level of satisfaction among parents of children with CI, with SMS text reminders for their appointments with the therapy centres.

METHOD

Study Participants

A total of 24 children with CI were enrolled in this study. The children were attending the AVT sessions at the Speech and Hearing Unit, ENT department of Post Graduate Institute of Medical Education and Research Chandigarh, a premier tertiary care centre in India. Two groups (study group and control group) were formed, with each group comprising 12 recipients of cochlear implants.

Inclusion criteria:

- Children with CI who were in the upper age range of 10 years and with no associated conditions like intellectual disability or cerebral palsy.
- Parents with access to a working mobile phone, who had at least five years of education and could read and understand simple Hindi sentences, and who consented to participate in this study.

Data Collection

In the study group, the phone number of each parent was entered in the SMS reminder message sending app and was synced with the Google calendar. A reminder SMS message was framed in Hindi, informing parents about their child's upcoming appointment, and prompting them to inform the clinician in case they were unable to visit on the scheduled day. The recurrent reminder schedule was set so that each parent received the reminder for therapy and mapping sessions 48 hours and again 24 hours before the scheduled session. The control group did not receive any reminders. Participants who rescheduled appointments ahead of time or arrived too late to be seen were coded as absent. Sessions that were cancelled by therapists were excluded from the analyses. At the end of three months, the data was analysed and 'no shows' were compared between the two groups.

Analysis

To find out the difference in the mean percentage of 'shows' in the study and control groups a *z-test for proportions was used*. The normality of data was tested using the *Kolmogorov-Smirnov normality test*. As the data was found to be normally distributed ($p > .05$), a 2-samples t-test was administered to find the mean difference in percentage of 'shows' between study and control groups, based on gender, age, implant age, and implant usage duration.

The parents who received the SMS reminders were asked to answer seven questions to evaluate the efficacy of the appointment reminder system from their perspective.

RESULTS

The attendance of both groups was analysed against the number of scheduled appointments. Characteristics of the study group and control group are shown in Table 1.1 and Table 1.2. The study group comprised 6 male and 6 female recipients, with a mean age of 6.01(± 2) years, mean age at implant surgery of 4.51(± 1.39) years and mean implant usage duration of 1.5($\pm .73$) years. The control group comprised 4 male and 8 female recipients, with a mean age of 5.63(± 1.53) years, mean age at implant surgery of 4.45(± 1.52) years, and mean implant usage duration of 1.18($\pm .7$) years.

The number of 'shows' and 'no shows' against the scheduled appointments of the study group and the control group are shown in Table 2. The number of 'shows' was 209 out of the scheduled 233 appointments in the study group, while the number of 'shows' in the control group was 173 out of the scheduled 232 appointments. The mean percentage of 'shows' was 90.47% (15.94) for the study group and 73.30% (13.38) for the control group.

Table 1.1: Characteristics of the Study Group **Table 1.2: Characteristics of the Control Group**

S. N	Gender	Age	Age at implant	Duration of CI usage
1	F	7.6	5.5	2.1
2	F	7	5	2
3	M	7.83	5.83	2
4	F	6.5	4.42	2.1

S. N	Gender	Age	Age at implant	Duration of CI usage
1	F	6.41	5	1.41
2	M	7	5.67	1.33
3	F	6	5.25	0.75
4	F	3.25	2.91	0.34

5	F	7.1	5.58	1.5
6	M	6.1	4.58	1.5
7	F	7	5.75	1.3
8	M	4	3.08	0.9
9	F	9	6.2	2.8
10	M	3	2.5	0.5
11	M	3	2.1	0.9
12	M	4	3.6	0.4
Mean (SD)		6.01 (2)	4.51 (1.39)	1.5 (.73)

5	F	5	2.25	2.75
6	F	5.92	3.9	2.02
7	M	8	7.3	0.7
8	F	3.5	2.84	0.66
9	M	5.5	3.92	1.58
10	M	3.75	3.16	0.59
11	F	5.83	5.16	0.67
12	F	7.4	6	1.4
Mean (SD)		5.63 (1.53)	4.45 (1.52)	1.18 (.7)

Table 2: Number of 'Shows' and 'No Shows' against the Scheduled Appointments of the Study Group and the Control Group

S. N.	Study Group				Control Group			
	Scheduled Appoint- ments	Shows	No shows	Shows (%)	Scheduled Appoint- ments	Shows	No shows	Shows (%)
1	18	18	0	100	18	12	6	66.67
2	15	12	3	80	21	13	8	61.9
3	24	21	3	87.5	15	9	6	60
4	21	21	0	100	20	20	0	100
5	21	21	0	100	12	9	3	75
6	31	30	1	96.7	22	16	6	72.72
7	21	21	0	100	18	12	6	66.67
8	12	12	0	100	20	14	6	70
9	28	20	8	71.42	16	10	6	62.5
10	15	15	0	100	22	22	0	100
11	18	9	9	50	22	18	4	75
12	9	9	0	100	26	18	8	69.23
	Total -233	Total -209	24	Mean- 90.47 (15.94)	Total -232	Total -173	Total - 59	Mean- 73.30 (13.38)

The comparison of the percentage of 'shows' in both the groups on the *z-test* for *proportions* as shown in Table 3 was statistically significant ($p < .05$). The percentage of 'shows' in the study group was significantly higher than that of the control group.

Table 3: Comparison of the Percentage of ‘Shows’ between the Study Group and the Control Group on the z- score Test for Proportions

S. N.	Group	Mean % of ‘shows’ (SD)	z-value	p-value
1	Study group	90.47(15.94)	4.34	.001*
2	Control group	73.30(13.38)		

* - Significant difference

As shown in Table 4, a 2-samples t-test was administered to find out the mean difference in the percentage of ‘shows’ between the study and the control groups, based on gender, age, implant age, and implant usage duration of the CI recipient children. When compared with the control group, the mean percentage of ‘shows’ was significantly higher ($p < .05$) in the study group for female recipients, recipients who were more than 5 years of age, recipients who were implanted after 5 years of age, and recipients who were using the implant for more than 1 year.

Table 4: Comparison of the Percentage of ‘Shows’ between the Study Group and the Control Group based on Gender, Age, Implant Age, and Implant Usage Duration, using

2-samples t-test

Characteristics of Participants		Mean (SD) percentage of ‘shows’ in the Study Group	Mean (SD) percentage of ‘shows’ in the Control Group	t-value	p-value
Gender	Male	89.03(19.72)	72.77(18.28)	1.31	.22
	Female	91.90(12.83)	73.57(11.75)	2.78	.02*
Age	<5 years	87.5(25)	86.25(16)	0.08	.93
	>5 years	91.95(11.12)	66.83(5.30)	5.76	.00005**
Implant Age	<5 years	89.53(18.9)	78.13(15.48)	1.23	.24
	>5 years	91.78(12.6)	66.56(5.98)	4.04	.004*
Implant Usage	<1 year	87.5(25)	78.61(17.27)	0.67	.52
	>1 year	91.96(11.12)	68(5.33)	4.84	.0004**

*- Significant; **- Highly significant

Parental Perception of Text Reminder System

At the end of the study a questionnaire was administered to the parents of children with CI, in order to evaluate their satisfaction with the SMS reminders. It had seven questions devised to know: whether they received the SMS message

reminders before every appointment; whether they found it helpful to get such an SMS text message and to indicate the level of helpfulness on a 10-point scale; whether they needed any additional form of reminder system; and, whether they informed the clinician in case they had to cancel an appointment. They were asked to compare the SMS service with other possible reminder systems. They were also asked to suggest improvements and to explain any difficulties faced with the SMS reminder system. The questions and the responses of parents of the subject group are given below.

Q1: Did you receive the SMS before every appointment?

All the parents reported that they received text messages before the scheduled appointments.

Q2: Do you think that getting text messages are beneficial to improve attendance?

Rate your satisfaction on a 10-point scale

All the parents reported that it was beneficial to receive the text messages before the scheduled appointments. On a scale from 1 - 10, eight parents (66.7%) reported the highest level of satisfaction (10 points) with text messages service, while 3 parents (25%) gave it 9 points and 1 parent (8.3%) gave it 8 points. Overall, parents reported a very high level of satisfaction with the SMS text reminders.

Q3: What other services are required to improve attendance, like phone calls, emails and postcards?

Ten parents (83%) reported only 'phone call' as an additional method, while only 2 parents (17%) reported both phone calls and emails to be used as additional methods to improve attendance.

Q4: How do you compare SMS texting with phone calls, emails, and postcards?

All the parents (100%) reported SMS texting as the best method for receiving reminders.

Q5. Did you inform the clinician about the cancellation of the appointment after receiving the SMS messages?

All the parents (100%) replied in the affirmative that they reported to the clinician about the cancellation once they received the SMS and could not attend the session.

Q6. How can we improve this service?

Nine parents (75%) reported that there was no need to use any other reminder method, while 3(25%) reported that telephone calls along with text messages may improve the text system.

Q7. What difficulties did you face with this service? (Did not see the SMS messages, message not received, got disturbed by the SMS messages)

None of the parents reported any difficulties with the text reminder system.

DISCUSSION

The present study was conducted to find the efficacy of the SMS reminder system in reducing the 'no shows' in the CI population attending therapy at a tertiary care centre. Two groups, comprising 12 CI recipients in each group, were enrolled in the study. The study group was enrolled for receiving the reminder SMS texts on their phones from the clinician's mobile Smartphone app. The parents received the reminders twice, i.e., 48 hours and 24 hours before the scheduled appointment for the AVT/mapping sessions. The control group did not receive any reminders. At the end of three months of therapy sessions, the number of 'shows' and 'no shows' were calculated for both the groups and compared. The study group had a significantly higher percentage of 'shows' than the control group. The reminder system targets the parents and the actual participants, i.e., children with cochlear implants who are dependent upon their parents for keeping the appointments. Hence the reminder system was effective for parents of children with cochlear implants to maintain appointment schedules with greater regularity as compared to the parents who did not receive the reminders.

In a review of seven studies with 5841 participants, it was found that mobile text message reminders improved the rate of attendance at healthcare appointments (Akhu-Zaheya & Wa'ed, 2017). In another study, the automated text message appointment reminders resulted in improved attendance at scheduled post-Emergency department discharge outpatient follow-up visits (Arora, Burner, Terp, Nok Lam, Nercisian, Bhatt & Menchine, 2015). In a study on the papillomavirus vaccination programme for low-income postpartum women, it was found that missed appointments for injections were less likely among those who received text message reminders (Berenson, Rahman, Hirth, Rupp & Sarpong, 2016).

However, there were many authors who could not find any significant difference in the number of 'shows' after using the reminder system. In a study on a dental outpatients' clinic, it was found that even with an increased number of SMS texts, higher attendance could not be ensured (Bellucci, Dharmasena, Nguyen & Calache, 2017). In a study directed at people in need of orthodontic treatment, reminder systems like telephone, mail, and SMS could not reduce the number of failed appointments (Bos, Hoogstraten & Prahl-Andersen, 2005). In a study with clients at higher risk of Sexually Transmitted Infections and HIV, the testing efficacy of SMS text reminders was evaluated for re-attending the clinic and was found to be not significantly different from not giving a reminder (Burton, Brook, McSorley & Murphy, 2014).

A few studies could not establish any significant relationship between the 'no shows' and the reminder system, although the reminders still had additional benefits including increasing medical knowledge (Richman, Maddy, Torres & Goldberg, 2016), increasing self-efficacy in disease self-management (Gatwood et al, 2016), and increasing the rate of taking medication on consecutive days (Stoner, Arenella & Hendershot, 2015).

The current study also tried to analyse the effect of age, gender, age at the surgery, and usage duration in children of both groups. Mothers, parents of children more than five years of age, and age at surgery, as well as those with more than one year of implant usage in the study group showed a significantly higher percentage of 'shows' when compared with the control group ($p < .05$). Parents of girls in the study and control groups seemed to be less motivated to attend AVT sessions, probably due to the prevailing social milieu in which girls get less preference than boys. Similarly, in both the study and control groups, parents of CI recipients who were more than five years of age seemed to be less motivated to attend AVT sessions. This could be due to the ceiling effect on language development in their wards and the parents' confidence that they could carry out therapy activities at home. The text reminders might have encouraged these less motivated parents in the study group to attend therapy sessions; their attendance increased significantly in comparison to the less motivated parents of the control group who did not receive any reminder. Given the small number of parents participating in this study, one needs to be careful in associating the above variables with adherence to appointments.

This study of the reminder system in the AVT group is the first of its kind. Considering the important requirement of intensive speech therapy for children

with cochlear implants, this study may be useful for many clinics to decrease the number of 'no shows'.

The questionnaire used in this study to measure the parents' perception of, and satisfaction with, the reminder system revealed that most parents are satisfied with this text reminder system and do not want any other reminder system. In another study, client satisfaction with text messaging ranged from 77% to 96% (Fischer et al, 2017). In a different study, subjects showed a clear preference for mailed reminders over telephone calls or SMS messages (Bos et al, 2005).

Limitations

There are a few limitations to the study. The number of 'no shows' in therapy sessions may be affected not only by parents forgetting the scheduled appointments but also by the level of motivation and awareness of the parents, the economic condition of the family, distance from the therapy centre, and the general health status of the child. These variables were not controlled in the study. It is a preliminary study and needs longitudinal data with a higher number of subjects to generalise the findings.

CONCLUSION

SMS text reminders via a Smartphone app is effective in facilitating a reduction in the 'no shows' for the speech therapy sessions and mapping sessions for persons with cochlear implants. Parents of children with CI showed a high level of satisfaction with SMS reminders. There is a need to conduct a similar study with a larger number of subjects and in different settings so that the results may be generalised. Such a study should consider controlling the variables like income, education level, distance from the therapy centres and motivation of the parents.

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Does Residing in Environments of Different Metropolises in a Developing Country have an Impact on Disability after Stroke?

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ABSTRACT

Purpose: *The study aimed to analyse the association between the environment in two different Brazilian metropolises (São Paulo and Belo Horizonte) and disability after a stroke.*

Method: *A cross-sectional study was conducted involving individuals with chronic hemiparesis resulting from a stroke and residing in either São Paulo or Belo Horizonte. The environment (city of residence) was considered an independent variable and disability (modified Rankin scale) was the dependent variable. The following clinical and demographic covariates were considered: age, number of comorbidities, socio-economic class, motor impairment (Fugl-Meyer scale), emotional functioning (Geriatric Depression Scale) and walking ability (10-metre walk test).*

Results: *A total of 114 individuals were analysed - 51 from São Paulo (SP) and 63 from Belo Horizonte (BH). No association was found between the environment in which the individual resides and the degree of disability (OR = 1.436; 95%CI: 0.547 - 3.770; $p = 0.46$). However, the following variables were predictors of post-stroke disability: motor impairment (OR = 0.216; 95% CI: 0.090 - 0.520; $p < 0.001$) and walking ability (OR = 0.066; 95% CI: 0.005 - 0.912; $p = 0.04$). The overall correctness of the model was 77.9%.*

Conclusion: *Living in different Brazilian cities had no impact on post-stroke disability. In contrast, motor impairment and walking ability were responsible*

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for 77.9% of the disability found in the sample. The study findings identify possible causes of disabilities after stroke; these could facilitate the most appropriate actions to be taken during rehabilitation.

Key words: *stroke, International Classification of Functioning, Disability and Health, environment*

INTRODUCTION

Projections show that about 3.4 million adults worldwide will have a stroke by 2030, which is a 20.5% increase in prevalence compared to 2012 (Mozaffarian et al, 2015). In a study on the burden of disease considering 369 health conditions, stroke was ranked the second major cause of disability in individuals older than 50 years of age (Vos et al, 2020). Leite et al (2015) estimated the causes of disability-adjusted life years (DALYs) in Brazil, highlighting the predominance of chronic non-communicable diseases, especially cardiovascular disease, in all regions of the country. In the southeastern region, cardiovascular disease accounts for 79.5% of DALYs which is the highest percentage of disability due to this type of disease among the five macro-regions (Leite et al, 2015).

Stroke is the fourth leading cause of DALYs across Brazil and the fifth leading cause in the southeastern region (Leite et al, 2015). Due to the high prevalence of stroke, it was one of the first health conditions to receive attention of different research groups who seek to study functioning according to the structure of the International Classification of Functioning, Disability and Health (ICF) (Barak & Duncan 2006; Tempest & McIntyre, 2006). This classification is based on the biopsychosocial approach, which integrates the different dimensions of health (biological, individual and social). In this model, disability and functioning are conceived as the dynamic interaction of body functions and structures, activity and social participation, considering contextual (personal and environmental) factors (World Health Organisation, 2001).

According to the ICF, the environment is directly related to disability and functioning. However, this relationship needs to be explored from different perspectives, including the comparison of different cities and states. Several international studies have identified environmental factors as risk factors for stroke or mortality, the most widely investigated of which are pollution, climatic conditions/seasonal effects, working hours and exposure to lead (Chang et al, 2014; Wilker et al, 2014; Han, Yi, Kim & Kim, 2015; Kivimäki et al, 2015; Hammel

et al, 2015, Zhang, Yan, You & Li, 2015; Cawood & Visagie, 2015; Feigin et al, 2016). A few studies have linked environmental factors to post-stroke disability; however, the study found on this topic was carried out in Canada, which is a country with very different socio-economic and cultural characteristics from those found in Brazil (Rochette, Desrosiers & Noreau, 2001).

In the Brazilian context, two large metropolises in the southeastern region - São Paulo (SP) and Belo Horizonte (BH) - are among the 10 largest cities in the country. The states of São Paulo (SP) and Minas Gerais (MG) are among the most populous states in Brazil and have a higher income in comparison to the national average (Instituto Brasileiro de Geografia e Estatística, 2018). Despite the similarities, a significant difference in life expectancy is found that cannot be explained by socio-economic factors (Chiavegatto Filho & Laurenti, 2013). Differences in lifestyle and risk factors may explain this divergence. Residents of SP are generally more sedentary than those of MG, whereas income per capita and level of education are higher in SP compared to MG (Chiavegatto Filho & Laurenti, 2013). These divergences may also contribute to differences in the degree of post-stroke disability.

Objective

Contextual characteristics related to the environment are often inherent to the decision-making process regarding rehabilitation and therefore need to be identified and considered, especially if such characteristics exert an influence on functioning and disability in health conditions as impactful as a stroke. Therefore, the aims of the present study were to evaluate the association between the environment in different cities (SP and BH) and disability following a stroke and determine predictors of post-stroke disability.

METHOD

Study Design

A cross-sectional study was conducted, involving residents of São Paulo (SP) and Belo Horizonte (BH) with chronic hemiparesis due to a stroke. The participants were evaluated at the physical therapy outpatient clinics of Universidade Nove de Julho and Universidade Federal de Minas Gerais located in São Paulo and Belo Horizonte, respectively.

Study Sample

All the participants had to be residents of either SP or BH and have mental competence, which was determined using the Mini Mental State Examination with the cutoff points described by Bertolucci, Brucki, Campacci & Juliano, 1994.

Inclusion criteria:

Individuals aged 18 years or older, with a clinical diagnosis of primary or recurrent stroke for more than six months that resulted in hemiplegia/paresis.

Exclusion criteria:

Individuals with any other neurological condition beyond stroke, and those with motor or comprehension aphasia (assessed by the ability to speak during a simple conversation).

The final sample was composed of 114 participants (51 from the city of SP and 63 from BH).

Variables

Dependent variable - Disability was the dependent variable and was measured using the modified Rankin scale (Salgado, Ferro & Oliveira, 1996). Two categories were considered for the analysis in the present study: no disability/mild disability versus moderate/severe disability (Salgado, Ferro & Oliveira, 1996).

Independent variable - The environment (residing in SP or BH) was the major independent variable.

Covariables

Factors that could be related to post-stroke disability were considered covariables. For this study, the covariables were described considering the framework of the ICF biopsychosocial model based on references that related this model to stroke (Salter et al, 2005a; Salter et al, 2005b; Salter, Jutai, Teasell, Foley & Bitensky, 2005; Barak & Duncan 2006; Silva et al, 2015): **Body functions component** - motor impairment and emotional functioning, measured using the Fugl-Meyer scale and Geriatric Depression Scale, respectively (Salter, Jutai, Teasell, Foley & Bitensky, 2005); **Activity component** - walking ability and mobility, measured using the 10-metre walk test and the Timed Up and Go test, respectively (Salter et al, 2005b); **Participation component** - Stroke-Specific Quality of Life score (Silva

et al, 2015); and **Personal factors** - sex, age, number of comorbidities, marital status and socio-economic class (see Figure 1).

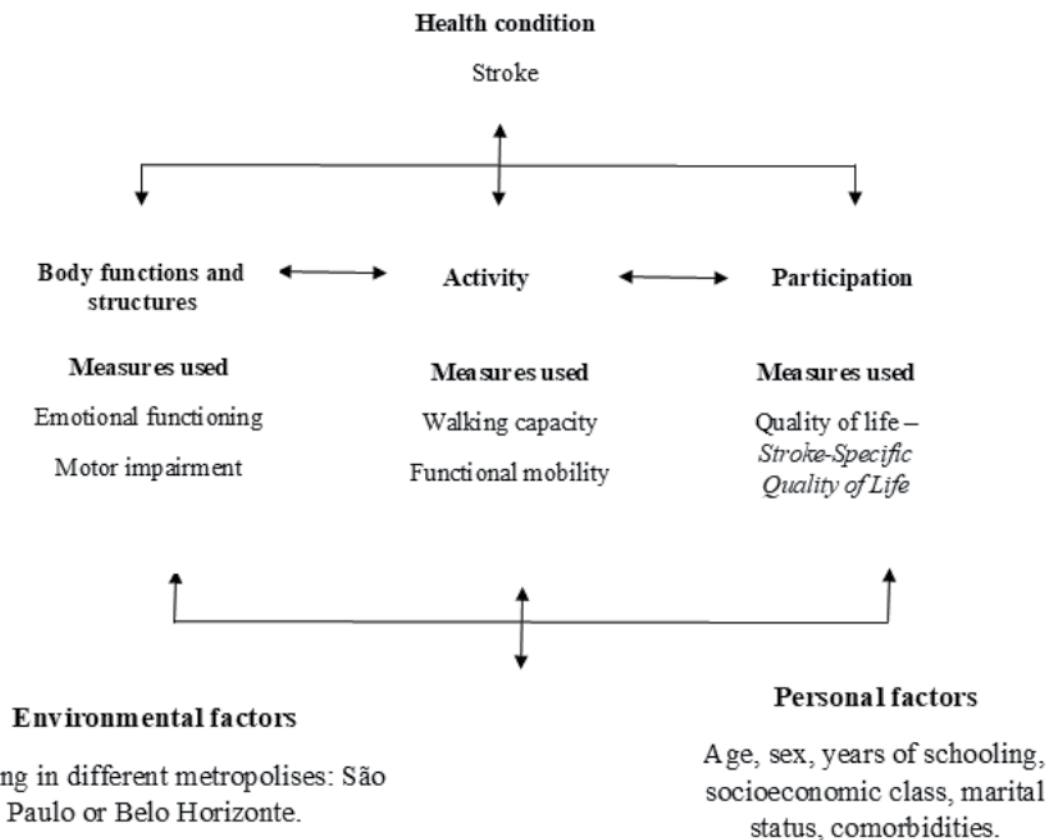


Figure 1: Data organised according to the Framework of International Classification of Functioning, Disability and Health applied to Stroke (Adapted from World Health Organisation (WHO)/Pan American Health Organisation (PAHO))

Causal Diagram of Association between Environment and Disability

Among the variables in Figure 1, were selected those that could conceptually be involved in confounding mechanisms according to a theoretical model represented in a directed acyclic graph (DAG). The DAG was created using the DAGitty programme and enables the identification of sets of variables to perform a conceptually valid adjustment in the estimation of the exposure-outcome association of interest (Textor, Van Der Zander, Gilthorpe, Li Skiewicz & Ellison, 2016). The DAG is preferable to the traditional model for identifying confounding variables, especially when the research question is complex (Suttorp, Siegerink, Jager, Zoccali & Dekker, 2015).

The DAG establishes a causal link between variables. When two variables are not directly connected, this implies independence which may be conditional or not to other variables. Following this assumption, a causal diagram was created to identify the adjustment variables in the analysis of the association between disability and environment (SP or BH). To be included in the causal diagram, a variable should have been previously associated with disability after stroke and measured using an appropriate measurement instrument for the population in question.

Before modelling, consistency between the DAG and the data was evaluated by testing the implications of independence suggested by the diagram (Textor, Van Der Zander, Gilthorpe, Li Skiewicz & Ellison, 2016). To test these implications, the significance level was set at ≤ 0.005 (significance adjusted by the Bonferroni correction for 10 tested independence implications) as a criterion for revising the DAG. Covariables that did not alter the estimate of interest by more than 10% and those not associated with the outcome were removed from the causal model. The variables that remained associated with the outcome were age, emotional health, number of comorbidities, motor impairment, socio-economic class and ability to walk. Thus, these variables were considered in the final model of the analysis between environment and disability.

Data Collection

Anthropometric, demographic and clinical data were collected using a standard assessment form containing information on personal and environmental factors. The participants were then submitted to evaluations by properly trained examiners.

Assessment Tools

All instruments employed have adequate measurement properties (validity and reliability) for use on stroke survivors (Fugl-meyer, Jaasko, Leyman, Olsson & Stegling, 1975; de Haan, Limburg, Bossuyt, van der Meulen & Aaronson, 1995; Almeida & Almeida, 1999; Salbach et al, 2001; Caneda, Fernandes, Almeida & Mugnol, 2004; Flanbsjer, Holmback, Downham, Patten & Lexell 2005; Marc, Raue & Bruce, 2008; Michaelsen, Rocha, Knabben, Rodrigues & Fernandes, 2011). All questionnaires had been adapted to Portuguese-Brazil (Almeida & Almeida, 1999, Caneda, Fernandes, Almeida & Mugnol, 2004; Michaelsen, Rocha, Knabben, Rodrigues & Fernandes, 2011) and all procedures recommended for

the application of the assessment instruments were duly followed (Fugl-meyer, Jaasko, Leyman, Olsson & Steglind, 1975; de Haan, Limburg, Bossuyt, van der Meulen & Aaronson, 1995; Almeida & Almeida, 1999; Salbach et al, 2001; Caneda, Fernandes, Almeida & Mugnol, 2004; Flanbsjer, Holmback, Downham, Patten & Lexell 2005; Marc, Raue & Bruce, 2008; Michaelsen, Rocha, Knabben, Rodrigues & Fernandes, 2011).

Geriatric Depression Scale

The Brazilian version of the Geriatric Depression Scale (GDS) was administered in the form of an interview and was used to assess emotional health, screening for depressive symptoms and mood disorders. The short 15-item version was used, which has adequate reliability and validity for the Brazilian population (Almeida & Almeida, 1999). A score above 5 points was considered positive screening for depression and a score above 11 points was considered indicative of severe depression (Marc, Raue & Bruce, 2008).

Modified Rankin Scale

Modified Rankin Scale (mRS) was created to measure the degree of disability and dependence on activities of daily living following a stroke (de Haan, Limburg, Bossuyt, van der Meulen & Aaronson, 1995). The scale is scored as follows: 0 = no symptoms, 1 = no significant disability; 2 = mild disability; 3 = moderate disability; 4 = moderately severe disability; and, 5 = severe disability (de Haan, Limburg, Bossuyt, van der Meulen & Aaronson, 1995). The mRS has satisfactory validity and clinical reliability for the Brazilian population (Caneda, Fernandes, Almeida & Mugnol, 2004). For the purpose of analysis, two categories were considered: no disability/mild disability versus moderate/severe disability (Salgado et al, 1996).

Fugl-Meyer Scale

The Fugl-Meyer Scale (FMS) was used as a measure of upper and lower extremity motor impairment (Fugl-meyer, Jaasko, Leyman, Olsson & Steglind, 1975). It has satisfactory reliability and validity for the Brazilian population (Michaelsen, Rocha, Knabben, Rodrigues & Fernandes, 2011). The maximum score is 100 points: 66 points for the upper limb and 34 for the lower limb (Fugl-meyer, Jaasko, Leyman, Olsson & Steglind, 1975; Michaelsen, Rocha, Knabben, Rodrigues & Fernandes, 2011). The classification of global motor impairment is based on the total, with 50 points indicating severe motor impairment; 51-84 = marked

impairment, 85-95 = moderate impairment, 96-99 = mild impairment, and 100 = no motor impairment (Fugl-meyer, Jaasko, Leyman, Olsson & Steglind, 1975; Michaelsen, Rocha, Knabben, Rodrigues & Fernandes, 2011).

10-metre Walk Test

The ability to walk was analysed using the 10-metre Walk Test (10mWT) (Salbach et al, 2001), which is considered an important measure of functional performance and has adequate reliability for use on individuals with hemiparesis (Salbach et al, 2001). The protocol proposed by Flansbjerg et al (2005) was used and gait speed was calculated as metres per second (m/s) considering the average of three repetitions at each speed (comfortable and maximum) (Flansbjerg, Holmback, Downham, Patten & Lexell 2005).

Statistical Analysis

The Shapiro-Wilk normality test was used to analyse the distribution of the data. Variables with normal distribution were expressed as mean and standard deviation, categorical variables were expressed as frequency, and nonparametric variables were expressed as median and interquartile range. The statistics of the following variables were presented according to the environment (city of SP or BH): sex (male or female), number of comorbidities, socio-economic class (A1, A2, B1, B2, C1, C2, D and E), motor impairment (no impairment, mild, moderate, marked and severe impairment) and disability (no/mild disability and moderate/severe disability).

The sample size was calculated considering the inclusion of 6 covariables associated with the causal relationship between disability and environment determined in the causal model/diagram proposed in this study: age, emotional health, number of comorbidities, socio-economic status, motor impairment and walking ability. The formula $P = (n+1) \cdot 10$ was used, in which “n” represents the number of independent variables (Stevenson, 2021). Therefore, a minimum of 70 participants were needed for the present study.

Binary logistic regression was used to estimate the association between the environment (SP or BH) and disability (no/mild disability versus moderate/severe disability). In the first model, only the direct association between disability and environment was considered. In the second model, covariables identified in the causal diagram that could affect the association between environment and

disabilities were included: walking ability, motor impairment, socio-economic condition, comorbidities, age and emotional health.

After selecting the variables, multicollinearity was tested, considering a tolerance value >0.1 and VIF <10 . After analysing these requirements, the association between environment and disability was adjusted considering the following quality tests: χ^2 , Nagelkerke's R^2 and Hosmer-Lemeshow. The results were expressed in odds ratios (OR) and 95% confidence intervals (CI).

All statistical analyses were performed using SPSS for Windows (SPSS Inc., Chicago, IL, USA), version 20. All tests were bilateral and a significance level of $\alpha = 0.05$ was considered in all inferential analyses.

Ethical Approval

This study received approval from the Human Research Ethics Committee of Universidade Nove de Julho, São Paulo, Brazil (protocol number: 3.381.555). All participants signed a statement of informed consent and were made aware of the possibility of withdrawing from the study at any stage, without penalty.

RESULTS

In São Paulo, 97 stroke survivors were recruited but 22 of them were excluded for cognitive impairment, 15 for aphasia and 9 for having another disabling clinical condition besides stroke. In Belo Horizonte, 109 stroke survivors were recruited but 18 of them were excluded for cognitive impairment, 14 for aphasia and 14 because they were unable to perform all the tests. Thus, the final sample was composed of 114 participants (51 from the city of SP and 63 from BH).

The distribution of the sexes was even in both cities. However, the BH sample was slightly older and had more chronic post-stroke sequelae (Table 1). The BH participants also had a larger number of comorbidities; most individuals reported 4 or more comorbidities (82.3%), while the SP individuals had an average of 2.54 comorbidities and 35.3% reported only one comorbidity. The other clinical-demographic characteristics were similar in the two cities. The most frequent socio-economic class was C1 in BH (39.7%; $n = 25$) and C1 and C2 in SP (59%; $n = 30$). No individuals were categorised in classes A1 and A2 in either metropolis. The most prevalent level of education in both cities was complete primary education.

Table 1: Demographic and Clinical Characteristics of Sample

Variables	São Paulo n= 51	Belo Horizonte n=63
Male	28 (54.9%)	30 (47.6%)
Female	23 (45.1%)	33 (52.4%)
Age	55.17 ± 13.9	65.34 ± 11.68
Time since stroke event (years)	4.05 ± 4.18	5.03 ± 4.50
Marital status		
Married	30 (58.8%)	27 (42.9%)
Single	11 (21.6%)	10 (15.9%)
Divorced	7 (13.7%)	5 (7.9%)
Widowed	3 (5.9%)	21 (33.3%)
Number of comorbidities	2.54 ± 1.45	3.71 ± 0.65
Number of medications	4.28 ± 2.54	4.21 ± 2.38
Disability		
None	7 (13.7%)	18 (28.6%)
Mild	13 (25.5%)	16 (25.4%)
Moderate	18 (35.3%)	17 (27.0%)
Moderately severe	7 (13.7%)	6 (9.5%)
Severe	6 (11.7%)	3 (4.8%)
Motor impairment		
None	7 (13.7%)	5 (7.9%)
Mild	9 (17.7%)	9 (14.3%)
Moderate	12 (23.5%)	18 (28.6%)
Marked	15 (29.4%)	20 (31.7%)
Severe	8 (15.7%)	11 (17.5%)
Emotional health (GDS score)	4.5 (6.0)	6.0 (6.5)
Walking capacity (10mWT-m/s)	0.86 ± 0.32	0.75 ± 0.30

GDS: Geriatric Depression Scale; 10mWT: Ten-Metre Walk Test; m/s: metres per second.

Data expressed as absolute and relative frequency, mean and standard deviation or median and interquartile range.

In the simple model, the environment was not significantly associated with disability [$\chi^2(1) = 0.542$; $p = 0.46$, Nagelkerke's $R^2 = 0.011$] (OR = 1.436; 95% CI: 0.547 to 3.770; $p = 0.46$). In the multiple model which includes age, socioeconomic class, emotional health, motor impairment and ability to walk, the environment also showed no association with the outcome [$\chi^2(14) = 36.282$; $p = 0.46$, Nagelkerke's $R^2 = 0.551$]. In this model, motor impairment (OR = 0.22; 95% CI: 0.09 to 0.52, $p < 0.001$) and walking capacity (OR = 0.07; 95% CI: 0.005 to 0.912, $p = 0.04$) were independent predictors of disability (Table 2), with a predictive capacity of 77.9%. The other independent variables were not retained in the model.

Table 2: Modelling for Adjustment of Association between Environment and Disability

Variables	Odds ratio	95% CI β		<i>p</i>
		Lower	Upper	
Environment (SP or BH)	2.85	0.54	15.13	0.22
Age	1.02	0.96	1.09	0.57
Emotional health	1.04	0.86	1.25	0.70
Comorbidities	1.01	0.44	2.34	0.98
Motor impairment	0.22	0.09	0.52	0.001*
Socioeconomic class	0.89	0.50	1.56	0.68
Walking capacity	0.07	0.005	0.91	0.04*

* $p < 0.05$; OR: odds ratio; CI: confidence interval

DISCUSSION

The present study tested whether living in different Brazilian cities (SP and BH) can exert an influence on post-stroke disability. After the analysis of the results, no association was found between the environment in which an individual resides – considering the two cities studied – and the degree of disability. In contrast, motor impairment and walking ability explained 77.9% of the disability found in the sample.

The proposed estimation model of the association between environment and disability was based on the biopsychosocial model of the ICF, therefore considering the influence of different components on disability and functioning. The analysis of the implications of independence tested in the final diagram revealed that

the measure related to the participation component was not associated with the outcome. However, it should be noted that the measure employed to measure participation refers to the score on a health-related quality of life questionnaire, which has previously been used for this purpose (Salter et al, 2005a; Silva et al, 2015). Therefore, the score of the questionnaire is related to factors associated with other components of the ICF model (Pereira et al, 2019), which is likely why it was in line with other measures and was not retained in the implication test of the association diagram. Future analysis models of the association between disability and the environment should consider more specific measures of participation after a stroke, such as SATIS-Stroke, which measures satisfaction obtained in activities and participation after a stroke (Pereira et al, 2019).

According to the ICF, the environment can be either a facilitator or barrier in the process of human disability and functioning (World Health Organisation, ©2001)©. This subject has been recurrent for decades but remains underexplored. Rochette, Desrosiers & Noreau (2001) analysed associations between personal and environmental factors and the occurrence of situations of disability after a stroke. However, the authors employed different methods from those used in the present investigation, using the Measure of the Quality of the Environment (MQE) for the analysis of the environment and the Assessment of Life Habits (LIFE-H) for disability. The authors concluded that obstacles perceived in the environment, together with age and level of physical incapacity, explained 58.9% of the variation in the LIFE-H score (level of disability). When considered alone, however, perceived obstacles (total score) explained only 6.2% of disability. Moreover, perceived facilitators (total score) in the environment were not related to situations of disability.

These results are partially similar to the findings of the present investigation, as motor impairment and the ability to walk were identified as significant predictors for post-stroke disability, with a predictive capacity of 77.9%. Desrosiers, Noreau, Rochette, Bravo & Boutin (2002) confirm the significant association between level of disability and post-stroke physical incapacities, with the coordination of the lower limbs, duration of rehabilitation, balance, age and comorbidities explaining 68.1% of situations of disability after six months of intensive rehabilitation. However, no influence of the environment was identified in the present study, whereas Rochette, Desrosiers & Noreau (2001) reported that the perception of obstacles may help explain post-stroke disability, albeit accounting for a very low percentage. The methodological differences between the studies may have

influenced these findings, as the MQE assesses the physical and attitudinal environment and, in contrast, the comparison of physical environments of different cities (SP and BH) may not be enough to detect any influence on disability.

Specifically, regarding SP, there is no data on the association between disability and the environment. However, both physical inactivity and fear of violence have been identified as factors that mediate the association between income and self-perceived health (Chiavegatto Filho, Lebrão & Kawachi, 2012). In BH, more data is available on disabilities. Felicíssimo et al (2017) investigated associations with socio-economic status and comorbidities. The prevalence of self-reported disability was 10.43% and disability was associated with age, two or more comorbidities and socio-economic status. Thus, a poorer socio-economic position and the occurrence of diseases seem to contribute to the occurrence of motor, visual and hearing impairments. In the present study, however, no association was found between socio-economic status and disability. This may be explained by the homogeneity of the SP and BH groups with regard to socioeconomic class. Perhaps different results would be found in the comparison of these findings with different regions of Brazil, particularly the northern and northeastern regions, due to the considerable socio-economic and cultural differences.

Giacomin, Peixoto, Uchoa & Lima-Costa (2008) estimated the prevalence of functional disability among older people living in the metropolitan region of BH and analysed associated characteristics. The prevalence of disability was 16% (8% mild and 8% severe). Age and a poorer self-perception of health were positively and independently associated with mild and severe disability. Chronic diseases, such as hypertension and arthritis, were associated with mild or moderate disability, whereas diabetes and stroke were associated with severe disability. In contrast, no associations were found between post-stroke disability and age or number of comorbidities in the present study, despite the fact that the BH residents were older and had more comorbidities.

Regarding emotional health, Clarke, Black, Badley, Lawrence & Williams (1999) found that depressive symptoms were associated with disability 3 and 12 months after the stroke. In contrast, emotional health did not exert an influence on post-stroke disability in the present study, although the BH residents had a median of 6.0 points on the GDS, which is considered a positive sign of depression, whereas the median among the SP residents was 4.5 points (without depressive signs).

Limitations

The main limitation of this study pertains to the cross-sectional design, which does not enable the establishment of temporal relationships between the independent variables and disability. Another limitation is the division of the groups into “no/mild disability” vs. “moderate/severe disability”, which, although guided by the literature (Salgado et al, 1996), can limit the analysis of different levels of disability. This was done due to the sample size which was not sufficient to divide the participants into five groups. Another important limitation refers to the fact that, although the authors have been guided by the ICF biopsychosocial model, the use of mRS can limit the findings, since this scale is not based on the ICF concepts for assessing disability and does not consider the influence which the environment has on disability. Moreover, no measure of activity related exclusively to upper limb function was evaluated; only total motor impairment of the lower and upper limbs (measured using the FMS) was considered.

Despite these limitations, the present findings are extremely relevant, since motor impairment and the ability to walk explained 77.9% of post-stroke disability in the chronic phase, which is higher than the predictive value reported in previously published studies with similar objectives (Rochette, Desrosiers & Noreau, 2001; Pereira et al, 2019).

CONCLUSION

In conclusion, although no significant association was found between the two metropolises evaluated and disability, the model proposed herein identified motor impairment and the ability to walk as predictors of disability after stroke, with an overall correctness of the model of 77.9%. Future studies should investigate whether similar results are observed in other cities that have different socio-economic characteristics from those considered in the present study.

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This study was financed in part by the following Brazilian grant agencies: Coordenação de Aperfeiçoamento de Pessoal de Nível Superior (CAPES) – Finance Code 001, Fundação de Amparo à Pesquisa do Estado de Minas Gerais (FAPEMIG), Conselho Nacional de Desenvolvimento Científico e Tecnológico (CNPq), and Pró-reitoria de Pesquisa da Universidade Federal de Minas Gerais (PRPq/UFMG). This financial support provides scholarships and grants. CAPES,

FAPEMIG, CNPq, and PRPq/UFMG are not involved in any other aspects of this study.

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REVIEWS

Self-Advocacy and Ally-Advocacy for Disability Justice: Organisational, Psychosocial, and Political Resources

Henry McCarthy*

ABSTRACT

The world of today sees more persistent, collective work of marginalised people resisting structural oppression rooted in racism and misogyny through newly-organised multinational movements like Black Lives Matter, #IamSpeaking, and Me Too. This has led to a rapid rise in public consciousness and activism about social injustices across many sectors of society. Ableism and other types of discrimination in education, employment and community-living experienced by people with a disability have both similarities to, and differences from, the indignity and impact of racism and misogyny. The activist disability community is working hard to have their advocacy agendas gain more public awareness and support. The common ground among all oppressed groups is their demand to have their human rights honoured. This requires two societal value shifts: (1) listening to voices outside the dominant culture and power structures through the involvement of insiders, based on their lived experience as members of the marginalised groups, and (2) collaborative advocacy to achieve milestones on their journey towards social justice. Applying these principles, this article aims to elevate and amplify the historical and current activities of self-advocates from the disability community to affirm and secure their human rights. The article provides explanations and examples of: (1) the complexities of disability-based discrimination; (2) political activism by the disability rights and independent living movements in the United States; (3) the psychosocial dimensions of embracing disability identity, culture, and pride; and (4) various outstanding consumer-driven artistic and organisational resources that are shaping the evolution of equal opportunity and disability justice.

Key words: *disability pride, human rights, self-help organisations*

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INTRODUCTION

Traditionally, disability was perceived as a defect or deficit in the individual, signifying dependence and misfortune. Over the past half-century, persons with disabilities and their allies have collaborated to replace these disparaging attitudes with a more realistic and affirmative understanding of disability as a virtually inevitable human variation that can be transcended by environmental accommodation and social inclusion. While disability has indeed been a source of multi-dimensional social injustice, it also fosters for many a positive socio-cultural identity and can serve as a transformative experience for living a more meaningful life. For individuals with disabilities not yet experienced in self-advocacy, this article offers perspectives and resources for learning about the disability community's agendas, accomplishments, and continuing contributions to improving their quality of life and making a society more equitable and fulfilling for all. That learning can inspire and strengthen all such individuals' journey of self-discovery and justice in pursuing their potential. A sense of empowerment can be nurtured by knowing about the ingenuity and perseverance of people who have had comparable challenges and have turned around their situations, getting past entrenched barriers to social equality by fighting for their human rights and personal dreams. For people without disability from the service professions or community at large, it is hoped that this article will promote further exploration, discussion, and application of an understanding of disability issues that will allow them to become effective allies.

By way of clarification, the term "disability" is broadly used throughout this article to encompass persons with various types of physical, intellectual, or behavioural limitations or disparaged differences that have resulted in their being excluded and stigmatised. **Disability justice** is conceived as removing systemic barriers to, and providing accommodating support of, human rights, social inclusion, and self-determination of people with disabilities. At least as early as 1960, Wright (pp. 7-8) recognised the disadvantages of reductionistically equating a person with a medical condition (e.g., he is an epileptic), so person-first language was recommended when writing and speaking about persons with disabilities. This principle is now widely followed to affirm the holistic humanity of those who have been disparaged and pigeonholed by a disability label. However, not everyone endorses using person-first language, including those who assert their preference for claiming and using the term "disabled" because of their deep sense of pride in that identity and experience. In recognition of this dual validity of insiders' own

preference in self-referencing terminology, both usages are incorporated into this article. See Dunn and Andrews (2015) for a fuller discussion of this issue.

COMPLEXITIES OF DISABILITY-RELATED INDIVIDUAL DISCRIMINATION AND SYSTEMIC OPPRESSION

In many countries, of any single demographic characteristic, having a disability is the strongest predictor of living in poverty. In turn, poverty has a negative impact on one's ability to engage in activities that promote educational attainment, healthy development, and safe living. The disability experience is slowly being included within the scope of multicultural sensitivity and social justice issues that are of increasing interest in contemporary agendas of academia, business, and governments around the world. This is evidenced by the addition of competence in addressing disability issues to human service professionals' codes of ethics, corporate personnel and customer-relations practices, and public policy priorities. National legislation that prohibits discrimination against persons with disabilities in education, employment, and community participation usually parallels and sometimes precedes progressive changes voluntarily made by autonomous academic, corporate, and community organisations.

Grasping the impact of oppression requires understanding and sensitivity about the varied ways in which it operates and is expressed. **Ableism** is ingrained systemic discrimination against people with disabilities, whether the disparaged difference is functional or simply aesthetic. It is called ableism because it sets and maintains standards of acceptability based on the capabilities and preferences of the able-bodied majority, rather than thinking outside the ingrained routines to consider the real range of individual needs and workable options in any performance situation. Although created often in a taken-for-granted way, ableist assumptions nonetheless lead to the imposition of physical or procedural structures that are riddled with barriers to access and inclusion for people who cannot use their eyes, hands, legs, etc., in "normal" ways. In contrast, the concept and principles of **universal design** maximise the participation of people with a wide spectrum of functional abilities and methods, because its goal is to make the designed result as easily usable by as many potential users as possible, not to force the person to fit the design. Although the concept originated in the fields of architecture and engineering, it has also been effectively applied to behavioural disciplines like communications and education (e.g., Bowe, 2000). This quote by Montgomery (2004) capsulises the goal of universal design incisively:

"I see the situation disabled people are in as unjust, not tragic. Created and sustained by society - which is to say, by all of us - and therefore potentially changeable. I'm not interested in changing myself into the sort of person society automatically enables; I'm interested in changing society so that it enables all its members."

An awareness training manual edited by Johnson (2006) is a great resource for understanding the evidence of ableism in our everyday world and for sensitising people to ways of combating it.

Hahn (1993) developed a theory about unconscious reactions to disability as a stimulus in interpersonal situations. He cogently argued that when people without disability encounter a person who has a visible disability, two emotional reactions are often stimulated by our primitive-brain impulses. He termed these apprehensions felt by observers: (1) *aesthetic anxiety* (discomfort at being close to bodily disfigurement or deviant appearance because it reminds them that they too are vulnerable to acquiring such losses of bodily function or integrity); and (2) *existential anxiety* (unconscious threat felt to their own safety and existence by seeing disability and subconsciously associating it with traumatic or fatal accidents). Hahn suggested that these anxieties are a major contributor to negative attitudes and dysfunctional behaviours regarding disability. Thus, purely on the basis of how our minds make such implicit negative associations, people (including educated professionals) may inadvertently avoid or mishandle important interactions with people with disability. Such anxious and foreshortened interactions can easily lead professionals to underestimate the capacities or to misinterpret the intentions of a client or colleague with a disability.

There is notable within-group variability in how discriminatory behaviour is interpreted and responded to by individuals from any marginalised group. Reactions include anger, shame, internalised inferiority, self-protective strategies, and avoidance of precipitating situations or strategically responding to expressed prejudice out of a desire to understand and educate the offending person or institution. *Intersectionality* is a relevant concept that deserves mention here. It refers to the fact that many people have layered or interacting identities reflective of more than one socially marginalised group. Self-identifying or being perceived as part of such multiple groups often exacerbates or complicates persons' experience of discrimination. Although further exploration of the impact of intersectional identities is beyond the scope of this article, readers should: (1) consider intersectionality of identities in their work with students,

clients, families and colleagues; and (2) engage in further learning as needed on this topic through reading, reflection, discussion, and awareness training. Some recommended publications include: Shaw, Chan and McMahon (2012) and Goethals, De Schauwer and Van Hove (2015).

POLITICAL ACTIVISM THAT HAS ADVANCED DISABILITY JUSTICE: THE DISABILITY RIGHTS AND INDEPENDENT LIVING MOVEMENTS

It was the interwoven, persistent activities of the disability rights movement (DRM) and the independent living movement (ILM) of the 1960s and beyond that generated the powerful, concrete demonstrations of a paradigm shift in perceiving and managing disability. These movements' trailblazers deconstructed the dominant medical model's narrow definition of disability as a problem within the person that needs to be cured or corrected by changing the person. Alternatively, they explained how external factors like inaccessible environments, paternalistic attitudes, and discriminatory policies create the real and unnecessary problems of living with a disability. Accordingly, a clearer term for this conceptual perspective, known in academia as the social model of disability, is believed to be the **self-determination philosophy** of the ILM and the **human-rights platform** of the DRM.

The most extensive and impressive source of information about the ILM and DRM in the United States is by Fred Pelka (2012). It is a delightful read in one long, well-annotated volume composed mostly of his original interviews with activists or similar interviews excerpted from the Oral Histories and Archives project on Disability Rights and the Independent Living Movement (www.bancroft.berkeley.edu/collections/drilm/index.html). Other informative and interesting accounts of these movements and their leaders include: Charlton (1998); McMahon and Shaw (2000); Fleischer and Zames (2001); McCarthy (2003); and, Davis (2015). The DRM and ILM have been largely composed of people with physical disabilities such as musculoskeletal, neurological, or sensory conditions that did not affect mental functions. Corresponding activism by people whose only or primary condition is intellectual disability is usually called the **self-advocacy movement**, and Caldwell (2011) is a fine example of similar research on its leaders.

Certainly there were efforts demanding equal opportunity by small groups of self-advocates with disability throughout the world and earlier in the 20th

century. However, the Zeitgeist of activism demonstrated by the Black civil rights, women's, American Indian, and gay rights movements of the 1960s was a momentous impetus for frustrated persons with disability to organise and self-advocate. A clear example of that occurred in the hotbed of that era's liberation movements, the University of California- Berkeley (UCB). In 1962, Ed Roberts enrolled in UCB, which has competitive admission standards. Ed's acceptance involved one extra hurdle: getting the administration to admit its first resident student with a significant physical disability. As a polio survivor with a paralysed diaphragm and extremities, he required personal care assistance and ongoing use of a respirator, a portable one attached to his electric wheelchair by day and a full-body "iron lung" in which he slept at night. Despite such physical dependencies, and through his persistent self-advocacy, he convinced the administration to allow him to live on campus, in a dedicated section of the University Infirmary where staff were available to provide assistance. Given the pervasive social expectation of that time, that people with that level of disability would not pursue higher education and a career, it is a tribute to UCB that they were able to think outside the box of these accepted norms to give Ed a chance and eventually support the self-help Physically Disabled Students' Programme he organised. It became the Centre for Independent Living (CIL) (www.TheCIL.org) in 1972 and moved off-campus in 1975. There, services were provided that included wheelchair repair, referrals to accessible housing, and career-development assistance, all provided through peer-counselling and peer-teaching. It has been the model for more than 400 IL Centres in the United States as well as similar programmes in 20 other countries. Ed died in 1995, widely acknowledged as the founder of the IL movement in the U.S.

PSYCHOSOCIAL RESOURCES THAT EMPOWER SELF-ADVOCACY: DISABILITY IDENTITY, DISABILITY CULTURE AND DISABILITY PRIDE

The following excerpt is a good starting point for describing these inter-related psychosocial concepts:

"People with disabilities have forged a group identity. We share a common history of oppression, and a common bond of resilience. We generate art, music, literature, and other expressions of our lives and our culture, infused from our experience of disability. Most importantly, we are proud of ourselves as people with disabilities. We claim our disabilities with pride, as part of our identity."

(“What We Mean by Disability Culture” link at www.instituteondisabilityculture.org) All three are multidimensional processes that evolve over time within most persons with disability. Most succinctly, the processes concern the different choices persons with disability can make regarding the degree to which they: (1) integrate that aspect of their selves, the acknowledgment of their disability, into their self-definition (disability identity); (2) develop an identification and preferential affiliation with others who offer the connections of understanding the disability experience and investing energy in both celebrating its unique opportunities and reducing its social marginalisation (disability culture); and (3) present a self-concept that embraces one’s disability experience as a source of personal strength and not shame (disability pride).

The topic of disability identity development was the most easily understandable of the three concepts, because there was an established history of related theory and research, for example on racial and feminist identity development. Interesting analyses of disability identity and activism that span three decades include: Scotch (1988); Gill (1997); and Forber-Pratt and Zape (2017). Disability culture emerged from ideological and sociological discourse in academia and the arts, starting around 1990. Some significant publications on disability culture are Linton (1998), Longmore (2003), and Riddell and Watson (2003). In the U.S., the academic discipline of disability studies and its flagship organisation, the Society for Disability Studies (www.disstudies.org), are the main engines of scholarship and mentoring that have successfully promoted both the political and psychosocial aspects of the disability experience. Putnam (2005) hypothesised that disability pride is one component of disability identity; and that it consists of four affective-cognitive elements. These are: (a) affirmatively “claiming” disability (a term chosen to contrast with the typical therapeutic goal of “accepting” one’s disability); (b) seeing impairments as a natural part of the human condition; (c) believing disability is not inherently negative, although it is frequently interpreted so; and (d) experiencing disability as a journey of developing a consciousness and identification with a cultural minority group.

At least three subpopulations of disability culture or pride can be distinguished that share fundamental commonalities but usually operate within their own networks. One is composed primarily of people with obvious physical disabilities. For them, access and accommodations for blindness and wheelchair mobility have been major issues; assertive personalities and effective communication skills have been their notable strengths. This group is predominant among the trailblazers

and current participants in the ILM and adapted competitive sports such as the Paralympics. There are several publications that reflect this community's perspectives and agendas. Prominent among them is the monthly magazine, *New Mobility*, which publishes both provocative and pragmatic articles. A second group is the Deaf culture, made up of people whose primary communication mode is sign language and who psychosocially self-identify with that culture. They do not experience the immediate reactions of being avoided, stared at, or given unwanted help that many people with visible physical disabilities have to handle. Instead, they experience significant isolation from mainstream culture because ability to communicate in sign language among the non-deaf population is very rare. People with chronic mental illness or past psychiatric histories comprise the third group. Typically, they do not encounter the physical or communication barriers just described. However, they bear the brunt of deep discrimination in the form of stigma, fearful rejection, and unreasonable or cruel treatment, even in allegedly therapeutic institutions. Schrader, Jones, and Shattell (2013) explained the evolution in self-advocacy priorities of this segment of the disability pride community, which they refer to as the mental-health consumer/survivor/ex-client movement. Its goals include: "articulate a broader culture of madness . . .the connections between madness and art, theatre, spirituality, and sensitivity to individual and collective pain . . . support interventions that target exclusion, poverty, trauma, and grief that contribute to distress and block positive adaptation".

EMERGENCE OF THE DISABILITY JUSTICE MOVEMENT

Like any group endeavours, the various movements for equity and self-determination by people with a disability have experienced their share of inter-group conflicts or dissatisfaction with some aspects of how the movements were operating. The following excerpts exemplify such a gap in groups' missions and capsulise how an evolving disability justice movement (DJM) distinguished its priorities from those of the DRM and the ILM. They are taken from the disability justice primer, 'Skin, Tooth, Bone: The Basis of Movement Is Our People' (Sins Invalid, 2019, pp. 15, 16, 18).

"While a concrete and radical move forward towards justice for disabled people, the Disability Rights Movement simultaneously invisibilised the lives of disabled people of colour...queers with disabilities, trans and gender non-conforming people with disabilities...people with disabilities who have had their ancestral lands stolen, amongst others."

“In 2005, queers with disability and activists of colour began discussing a “second wave” of disability rights. Many of these first conversations happened between Patty Berne and Mia Mingus, two queer women with disability of colour who were incubated in progressive and radical movements which had failed to address ableism in their politics...A single-issue civil rights framework is not enough to explain the full extent of ableism and how it operates in society. We can only truly understand ableism by tracing its connections to heteropatriarchy, white supremacy, colonialism, and capitalism.”

The DJM’s value-based principles include: viewing identity through a lens of intersectionality; leadership by those most impacted; commitment to cross-disability and cross-movement solidarity; and collective liberation (pp. 23-26). This 2nd edition (2019) of the disability justice primer contains chapters on diverse topics, such as Access Suggestions for Public Events, Principles of Mixed-Ability Organising, A Deeper Review into Deaf Culture, Disability Justice and Sexuality, as well as timelines of the movement’s milestones and a glossary. The text and images were collaboratively created by members of Sins Invalid, a DJ advocacy collective and “performance project that incubates and celebrates artists with disabilities, centralising artists of colour and LGBTQ / gender-variant artists as communities who have been historically marginalised” (<https://www.sinsinvalid.org/mission>).

The following roster of digital resources is representative of the creative and thoughtfully revolutionary quality of the DJM’s activities and impact:

- (1) The Disability Visibility Project is an online community founded and directed by Alice Wong that is dedicated to creating, sharing, and amplifying disability media and culture (<https://disabilityvisibilityproject.com/about/>).
- (2) Leah Lakshmi Piepzna-Samarasinha is a major activist, author and spokesperson within the DJM; her website (<https://brownstargirl.org>) is full of nurturant reflections and radical resources.
- 3) Leaving Evidence is a blog about transformative justice by Mia Mingus who explores in depth a variety of topics that provide: “Evidence of the wholeness we never felt and the immense sense of fullness we gave to each other. Evidence of who we were, who we thought we were, who we never should have been. Evidence for each other that there are other ways to live - past survival, past isolation”. (<https://leavingevidence.wordpress.com/media/>).

- (4) Project LETS (Let's Erase The Stigma) is a grassroots organisation led by and for folks with lived experience of mental illness/madness, disability, trauma, and neurodivergence, that specialises in building just, responsive, and transformative peer-support collectives and community mental-health-care structures that do not depend on state-sanctioned systems that trap people in the medical/prison-industrial complex.

SELECTED ORGANISATIONAL RESOURCES THAT ACTUALISE AND SUSTAIN DISABILITY JUSTICE

Based on their reputations of influence, the following roster of exemplary resources was selected from among many throughout the world that are doing excellent work in advancing disability justice on personal and societal levels. An acknowledged limitation of this list is that the organisations are primarily based in the U.S., which is the author's scope of direct experience. However, many of them have had considerable experience of either working directly in various other countries or consulting with fellow self-advocates from regions around the world, to respond to the changes taking place in society. These organisations embody the combination of political and psychosocial strategies and benefits of advocating for disability justice discussed above. These examples are offered as resources, so readers can learn from, be inspired by, and perhaps partner with them. To maximise the authenticity of the summaries, they were in large part excerpted and edited from the cited websites, with some of the author's findings or observations interwoven. Each summary was sent to a senior representative of that organisation, with the invitation to revise or elaborate on the information, as desired, for accuracy and meaningful utilisation by readers.

ADAPT (<https://adapt.org>) is a grass-roots community of disability rights activists engaged in nonviolent direct action and legislative advocacy to secure the rights of persons with disability to live in freedom. When founded in 1983, their name meant American Disabled for Accessible Public Transit, and their goal was to force city bus companies to install wheelchair lifts on all public buses. ADAPT members performed civil disobedience by chaining their wheelchairs to the front and back of buses, thereby disrupting the service and the street traffic to dramatise their message, "If I can't ride the bus, then you can't ride the bus." Most often they were arrested, which created additional problems for the police and jails that did not have the accessible infrastructure or knowledge to deal with arrestees with disability needs. Their peacefully disruptive demonstrations were

successful, which led ADAPT leaders to be invited to do activist self-advocacy training in many places. In 1990, they adapted their acronym to mean American Disabled for Attendant Programmes Today, because they changed their focal mission to shift the substantial federal funding of long-term care of persons with disability from corporate-owned nursing facilities to home-based support services. Currently, this advocacy is focused on achieving passage of the proposed legislation called the Disability Integration Act. It would ensure the right of all eligible citizens who need long-term services and supports to have the choice to live in their home in the community, instead of in a conglomerate facility. Such institutions are much less preferred by consumers and more expensive for the federal budget, but very profitable for the corporate owners.

Centre for Research on Women with Disabilities or CROWD (www.bcm.edu/crowd) is based at Baylor College of Medicine in Houston, Texas. Since 1993, original research has been conducted by CROWD's founder, Margaret Nosek, Ph.D., and her colleagues. Their research focuses on six priority categories: healthcare access; health promotion; psychosocial health; secondary medical conditions; sexuality and reproductive health; and, violence against women with disabilities. In addition, CROWD analyses others' research findings, which it synopsis and disseminates as brief summaries for health practitioners and consumers. Its website has an alphabetised directory of these research briefs as well as practical guidelines and resource lists on more than 50 topics in women's health and wellness. One unusual asset that CROWD offers is a virtual reality and social network tool through a Second Life programme (www.SecondLife.com). There are several "islands" in the programme that serve as spaces to connect with other users with similar real-world disabilities or to participate in virtual activities that might be challenging in real life. Their research is exploring how this form of virtual social activity affects participants' actual health behaviours (e.g., maintaining a weight-management programme). Dr. Nosek passed away in November 2020. She was not only a highly respected scholar but also a veteran of the DRM, as a protégé and close colleague of one of its most esteemed American leaders, Justin Dart, Jr. (1930-2002). Dart was often called the "father" of the Americans with Disability Act for his long-term commitment to the various conceptual, legislative, and promotional activities that made the Act a reality.

Disability Rights Education and Defence Fund or DREDF (<https://dredf.org>) was founded in 1978 and has grown tremendously in terms of the impact and scope of practice of its legal and advocacy work in the courts of law and the court of public

opinion. Its broad scope is reflected in the variety of subsections under its main programmes, such as: School-to-Prison Pipeline; International Disability Rights; Media and Disability; Foster Youth; and, Disability and Bioethics. In addition to the usual elements, its up-to-date and user-friendly website provides archived copies of its two electronic periodical communications, eNews and Special Editions, and a powerful statement on Diversity, Equity, and Inclusion regarding its own recruitment and employment practices that are a model for human resources departments to follow. It also has a link to 'The Power of 504', a documentary that recounts the effective occupation of a federal building in San Francisco, California, by several dozen disability rights activists in April 1977. They were protesting the government's prolonged procrastination in implementing Section 504 of the Rehabilitation Act of 1973, the first American civil rights law protecting people with disability. The video depicts this successful marathon of nonviolent civil disobedience that lasted 25 days and nights. Imagine the courageous commitment, ingenuity, and personal sacrifices made by these demonstrators to manage their significant disabilities in such an inhospitable space as an office building, without their own household and hygiene resources, while working non-stop on the bureaucratic negotiations and public relations required for the protest to succeed.

Disabled in Action or DIA (<https://www.disabledinaction.org>) is a civil rights organisation committed to ending discrimination against people with all disabilities. Organised in 1970 by Judy Heumann and some fellow activists at the Brooklyn campus of Long Island University, DIA is a democratic, not-for-profit, tax-exempt membership organisation directed by people with disability. Its objectives are to: (1) Raise consciousness among people with or without disabilities concerning ableism and paternalism, as well as laws and customs that oppress people with disability; (2) Promote the passage and enforcement of effective legislation and budget initiatives that affirm and defend the rights of people with disability to independent living and equal access in all areas of life; (3) Provide the organisational basis for activists with disability to join in effective, unified political action; and (4) Educate government officials, community leaders, institutional administrators, and the general public concerning disability rights issues by organising public demonstrations, participating in speak-outs and formal hearings, and obtaining press coverage of their activities. If they are not given access to the relevant power brokers in their offices and official meetings, DIA often engages in civil disobedience to get their attention and the support of the public. After directing DIA, Judy moved on to a succession of other executive

positions related to disability rights in government, non-profit, and corporate organisations (McCarthy & Johnson, 1995). She remains active in the DRM and recently published an autobiography (Heumann, 2020). Also, an impressive documentary, 'Crip Camp' that premiered in 2020, traces the experiences of Judy and fellow activists from their meeting in a summer camp for youth with disability in 1971 to the present day.

Disabled Peoples' International or DPI (www.dpi.org) is a non-governmental, human rights organisation founded in 1981 and comprising member organisations ("national assemblies") in 130 countries. It is headquartered in Ottawa, Canada, and has the motto, "A Voice of Our Own." Its mission is expressed through consensually created advocacy agendas, written as position papers related to legal or aspirational declarations, such as the Sustainable Development Goals (SDGs) that the United Nations adopted in 2015. Such a worldwide partnership poses the complex challenge of accommodating multiple languages, cultural values, and political structures among the member organisations involved. Therefore, it is not surprising that, especially compared to the other organisations summarised in this section, DPI is much more formal in its operations and reliant on parliamentary conventions. Nonetheless, its values are rooted in the elimination of the pragmatic economic, social, and health disparities experienced by millions of people with disability throughout the world. It is known for its productive advocacy work on the SDGs and the international treaty called the United Nations' Convention on the Rights of People with Disabilities (CRPD). The well-delineated toolkits DPI developed and disseminated to promote the ratification and subsequent implementation of the CRPD are available on the DPI website.

National Alliance on Mental Illness or NAMI (www.nami.org) is America's largest grassroots organisation dedicated to improving the lives of those affected by mental illness. Its website proclaims its core values. **Hope:** We believe in the possibility of recovery, wellness and the potential in all of us. **Inclusion:** We embrace diverse backgrounds, cultures and perspectives. **Empowerment:** We promote confidence, self-efficacy and service to our mission. **Compassion:** We practice respect, kindness and empathy. **Fairness:** We fight for equity and justice. Through its widespread network of 48 State chapters and 600 local affiliates, NAMI serves a huge constituency of mental health treatment consumers, self-advocates, family members, first responders, mental health professionals, veterans, and others in the community through a host of targeted programmes. These include:

10 types of educational courses and presentations; support groups; training in advocacy strategies; policy advocacy; public awareness activities; and, a Help Line that provides resource information and support.

Not Dead Yet or NDY: The Resistance (www.notdeadyet.org) is a grass-roots disability rights group that opposes legalisation of assisted suicide and euthanasia as deadly forms of discrimination against people with disability, young and old. It demands the equal protection of the law for these targets of “mercy killing” whose lives are perceived as worthless. Its website cogently explains its ideology and grave concerns about the consequences of adding assisted suicide to the list of “medical treatment options” available to people with disabilities. To those who counter that this option is given to persons who desire to end their life, NDY argues: “...society prizes physical ability and stigmatises impairments, it is no surprise that previously able-bodied people may equate disability with loss of dignity...the prevalent but insulting societal judgment that people with incontinence and other losses in bodily function are lacking dignity.” NDY explains how outrageous it is that while society urgently promotes suicide prevention, one socially devalued group is offered death by suicide assistance. A variety of educational modalities, advocacy strategies, protest actions, and legislative efforts are employed by NDY to carry out its mission nationwide.

People First (peoplefirst.org) is a model for self-help groups of persons with developmental, intellectual, and learning differences. It dates back to 1974 when, during the planning for a self-advocacy conference in Portland, OR, one of the self-advocacy pioneers participating in the planning objected to the repeated use of the words “retarded” and “handicapped.” He spoke up and declared: “*I want to be treated like a person first.*” From that came the group’s name, People First of Oregon, and the movement’s pithy motto: “Label jars, not people.” Additional groups of self-advocates have been organised in several cities in the U.S. as well as Canada, Germany, New Zealand, and the United Kingdom. People First has a sister-network of groups with a website called www.selfadvocacy.net, which is concerned with the broader self-advocacy movement and its hundreds of groups worldwide. That branch of the movement for self-determination by and for people with cognitive disabilities had its origins in 1968 in Sweden. That first group was formed in a very similar situation when budding self-advocates, at a meeting conducted by their parents, expressed their desire to speak for themselves and specified a list of changes they wanted in the services they were using.

Wheeling Forward (<https://wheelingforward.org>) is a non-profit, consumer-driven organisation created and managed by Yannick Benjamin and Alex Elegudin. They met in 2003 when they were roommates in the spinal cord injury rehabilitation programme at Mt. Sinai Hospital in New York City. Wheeling Forward is focused on promoting active lifestyles after acquiring a physical disability. From two locations in New York City, it offers an impressive array of programmes. Many of them are adapted versions of what are offered at the most expensive health and wellness clubs, such as: acupuncture and massage, art therapy and cooking classes, boxing lessons, Pilates and yoga, spinal mobility training and weight lifting. More unique services include: wheelchair maintenance; field trips to learn to navigate the marginally accessible subway system; and, outings to cultural events or sports experiences like water skiing or sky diving (McBride, 2018). Wheeling Forward also provides other resources to members in need: college scholarships with accommodation expenses included; donations of wheelchairs; personal advocacy on managing disability services or transition from nursing home to community living; and, facilitation of systems advocacy on local disability issues. Through their own experience of disability and their vision for improving their peers' quality of life, the founders have been enormously successful in a short period of time in creating the resources to energise an active community of people with disability who demonstrate personal fulfilment and disability pride.

Whirlwind Wheelchair International (<https://whirlwindwheelchair.org/>) was founded by Ralf Hotchkiss, based on his direct-user experience and visionary enthusiasm about integrating technology with pragmatic needs of those with mobility limitations. Before receiving a prestigious MacArthur Fellowship that enabled him to expand his organisation's reach, he had established this non-profit organisation through which he seeded several consumer-run, self-sustaining wheelchair shops in high-poverty regions worldwide. Working collaboratively with fellow wheelchair-users whom he recruits from each local community, they design wheelchairs that are made from locally available materials which are especially suited to endure the region's geological terrain (e.g., mountainous or swampy). In 60 countries, these shops also provide a much-needed vocational benefit, as they train and employ local persons with a disability to fabricate and service the wheelchairs.

CONCLUSION and IMPLICATIONS

The self-advocacy struggles and successes of the disability community have certainly improved the overall level of equity and accessibility of society. The process has also shaped stronger identities and expectations among the disability community for fair treatment in dealing with the broader society. Therefore, it is critical that service providers like physicians, teachers, counsellors, and the lay community at large become educated and motivated allies to support self-actualisation and social justice. They can do this by: (1) appropriately facilitating the journey by their clients and compatriots with disabilities to participate in all their desired domains of life with dignity and equity, and (2) combatting, within their immediate spheres of influence, the misguided paternalism and ableism to which people with disability have been historically and to-date subjected by most of society. The disability community and its experiences need to be centred and equally included in education programmes for helping professionals and the public at large to learn about cultural diversity and its impact, alongside other communities who have (a) experienced marginalisation and discrimination, but have also (b) enhanced the richness and evolving equity that societies and their service systems need to cultivate.

To be truly effective and ethical in promoting disability justice, it is essential for allies to approach advocacy work with humility and to do the work collaboratively. Checking on the acceptability and validity of their perceptions and motivations regarding advocacy work is their ongoing responsibility. This is done most meaningfully by: (a) listening to the experiences and desires of the least powerful stakeholders who are most affected by discrimination; and (b) asking how best to partner with them on the journey to expand their personal sense of empowerment or to address a social-structural problem oppressing their community. Individuals and institutions with research skills and resources can strengthen advocacy awareness and strategies by conducting applied studies based in the methodology and philosophy of **participatory action research**. Examples of such research topics that emerge from merely reflecting on principles discussed in this article include exploration of: (1) the ways in which contemporary political entities are enforcing, expanding, or impeding the legislative and policy achievements by the disability rights movements over the past 50 years; (2) guidelines for optimising meaningful use of technology and social media to reduce social isolation and promote disability pride among persons with both congenital and later-acquired disabilities; (3) the factors to which leaders of

exemplary self-advocacy organisations attribute their success, the lessons they learned, and advice or encouragement they would give to informal groups of self-advocates in less-resourced countries.

In addition to improving one's advocacy work as an allied professional or citizen, it is hoped that the contents of this article have offered readers useful personal applications. As living with a disability is an inevitable part of the life cycle for most people, learning and reflecting about genuine insider experiences of disability help everyone to acquire at least two types of personal life lessons. First, it can help in understanding ourselves better by exposing our stereotyped, dysfunctional assumptions about disability and, hopefully, stimulate us to recognise our own potential for managing current challenges. Second, specific strategies and resources can be learnt from the disability community that could help people deal with the possibility of functional losses in the future, by embracing a coping perspective and a sense of pride in the worthy, ever-changing, interdependent person each one is. This is why everyone deserves and benefits from a world where disability justice and human rights are embraced and enforced.

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

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

* * * * *

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

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Published by
Stichting Liliane Fonds
5211 TX's-Hertogenbosch
The Netherlands