DISABILITY, CBR & INCLUSIVE DEVELOPMENT

Formerly Asia Pacific Disability Rehabilitation Journal

Volume 33 ■ No. 3 ■ 2022

Contents

ORIGINAL RESEARCH ARTICLES

REVIEWS

BRIEF REPORTS

CASE STUDIES

LETTER TO EDITOR

Published by

Liliane Fonds

Supported by

NLR

Liliane Fonds

Website: www.dcidj.org

National Printing Press
580, K.R. Garden, Koramangala, Bangalore - 560 095, India.
Tel : 91-80-25710658 Email: nppbangalore@gmail.com

DISABILITY, CBR & INCLUSIVE DEVELOPMENT

Formerly Asia Pacific Disability Rehabilitation Journal

CONTENTS

Volume 33 ■ No. 3 ■ 2022

ORIGINAL RESEARCH ARTICLES

REVIEWS

BRIEF REPORTS

CASE STUDIES

LETTER TO EDITOR

Editorial
Rehabilitation for All?

In front of you lies a new issue of our journal in a (new) season of the year, Autumn. In the northern hemisphere, it symbolises and marks the beauty and satisfaction of harvesting on one hand but the decay of life on the other. In the southern hemisphere, it is Spring: the excitement of new life, rebirth, that become manifest in nature! I feel that in both seasons, nature is at its best and often catch myself looking in awe at the colours in the sky, the beauty of trees and plants. When the days become shorter, when the trees are leafless, when plants seem to have died and no flowers are to be seen in the wild, there is always the hope that that there will be new life again. In this "season of mist and mellow fruitfulness", I have the privilege to present the next issue of our journal.

It is an issue with a limited number of articles. Without denying the relevance of *any* of these articles, I was personally very interested in two of them, not without reason. The two articles I refer to are from South African authors and both discuss access to rehabilitation for all in South Africa. Most of you may know that I have lived in that country for 10 years, which is a quarter of my working life, and is the country where I developed a great interest in community-based rehabilitation approaches; purely because the conditions were asking for it. There is, however, a distinction made toward the focus of rehabilitation in the two articles. One deals with '**rehabilitation for all'** and the other with '**rehabilitation for people with disabilities'**. You may feel that I am splitting hairs here and if so, you are both right and wrong. In an ideal world there wouldn't be a difference. However, this world isn't ideal and unfortunately there is a difference whereby undoubtedly people with disabilities are the ones who – even in high income countries – experience far more barriers in accessing rehabilitation services than people without disabilities. The observant and well-informed reader may associate immediately the focus on 'rehabilitation for all' with the drive of the World Health Organisation and others to ensure that rehabilitation becomes part of universal health coverage. Those readers will also recognise that previously, the mission of the World Health Organisation and others was different. It focused on ensuring access to 'rehabilitation for people with disabilities' usually becoming manifest in so-called Community Based Rehabilitation. What thus is meant with rehabilitation in the current context of 'rehabilitation for all' means a narrow explanation of what rehabilitation is all about. What was or is meant with Community Based Rehabilitation is a much broader explanation of what rehabilitation is all about: a more eco-social explanation following all elements of the International Classification of Functioning, Disability and Health. But one that is 'restricted' or specifically focused at ensuring access to that broad form of rehabilitation for people with disabilities and their families because the reality is that this particular group was recognised by the World Health Organisation and others in the seventies and eighties of last century as a group of people who hardly had access to such comprehensive services and lacked equal opportunities. Does it mean that approximately 40 year later the situation is solved or is better for people with disabilities? The answers can be found in these two articles from South Africa, which, in comparison with all other African National States, has far more (rehabilitation)resources as well as progressive and far-reaching laws and legislation benefiting people with disabilities.

I truly hope that you will take the time to read those articles in detail; analyse them, critically review them and respond to either the authors or myself. I know it will mean that you have to set time aside for this. Yet, you as practitioner, scientist, policymaker, planner or manager must read what goes on in the world and critically review what developments have taken place; learn from it and realise how we can do things better. Let developments be made on basis of practical experience rather than on theoretical concepts, irrespective of how smart they seem to be. Isn't it time for the emancipation of the highly educated and influential ones? These days the policy towers contain largely people with scientific and policy knowledge, but unfortunately few with experiential knowledge.

Wishing you all very well and don't forget to respond to me at editor.dcid@gmail.com

Huib Cornielje
Editor-in-Chief
Disability, CBR & Inclusive Development Journal

GUEST EDITORIAL

COP27 Climate Change Conference: urgent action needed for Africa and the world

Wealthy nations must step up support for Africa and vulnerable countries in addressing past, present and future impacts of climate change

The 2022 report of the Intergovernmental Panel on Climate Change (IPCC) paints a dark picture of the future of life on earth, characterised by ecosystem collapse, species extinction, and climate hazards such as heatwaves and floods (IPCC, 2022). These are all linked to physical and mental health problems, with direct and indirect consequences of increased morbidity and mortality. To avoid these catastrophic health effects across all regions of the globe, there is broad agreement—as 231 health journals argued together in 2021—that the rise in global temperature must be limited to less than 1.5^{o}C compared with pre-industrial levels.

While the Paris Agreement of 2015 outlines a global action framework that incorporates providing climate finance to developing countries, this support has yet to materialise (United Nations, 2022). COP27 is the fifth Conference of the Parties (COP) to be organised in Africa since its inception in 1995. Ahead of this meeting, we — as health journal editors from across the continent — call for urgent action to ensure it is the COP that finally delivers climate justice for Africa and vulnerable countries. This is essential not just for the health of those countries, but also for the health of the whole world.

Africa has suffered disproportionately although it has done little to cause the crisis

The climate crisis has had an impact on the environmental and social determinants of health across Africa, leading to devastating health effects (Climate Investment Funds, 2020). Impacts on health can result directly from environmental shocks and indirectly through socially mediated effects (World Health Organisation, 2016). Climate change-related risks in Africa include flooding, drought, heatwaves, reduced food production, and reduced labour productivity (Trisos et al, 2022).

Corresponding Author: Chris Zielinski, University of Winchester, UK. Email: chris.zielinski@ukhealthalliance.org

Vol. 33, No.3, 2022; doi 10.47985/dcidj.656

Droughts in sub-Saharan Africa have tripled between 1970-79 and 2010-2019 (World Bank, 2021). In 2018, devastating cyclones impacted three million people in Malawi, Mozambique and Zimbabwe (World Bank, 2021). In west and central Africa, severe flooding resulted in mortality and forced migration from loss of shelter, cultivated land, and livestock (Opoku et al, 2021). Changes in vector ecology brought about by floods and damage to environmental hygiene have led to increases in diseases across sub-Saharan Africa, with rises in malaria, dengue fever, Lassa fever, Rift Valley fever, Lyme disease, Ebola virus, West Nile virus and other infections (Evans & Munslow, 2021; Stawicki et al, 2021). Rising sea levels reduce water quality, leading to water-borne diseases, including diarrhoeal diseases, a leading cause of mortality in Africa (Evans & Munslow, 2021). Extreme weather damages water and food supply, increasing food insecurity and malnutrition, which causes 1.7 million deaths annually in Africa (African Climate Policy Centre, 2013). According to the Food and Agriculture Organisation of the United Nations, malnutrition has increased by almost 50% since 2012, owing to the central role agriculture plays in African economies (UN Framework Convention on Climate Change - UNFCCC, 2020). Environmental shocks and their knock-on effects also cause severe harm to mental health (Atwoli et al, 2022). In all, it is estimated that the climate crisis has destroyed a fifth of the gross domestic product (GDP) of the countries most vulnerable to climate shocks (Vulnerable Twenty Group, 2020).

The damage to Africa should be of supreme concern to all nations. This is partly for moral reasons. It is highly unjust that the most impacted nations have contributed the least to global cumulative emissions, which are driving the climate crisis and its increasingly severe effects. North America and Europe have contributed 62% of carbon dioxide emissions since the Industrial Revolution, whereas Africa has contributed only 3% (Ritchie, 2019).

The fight against the climate crisis needs all hands on deck

Yet it is not just for moral reasons that all nations should be concerned for Africa. The acute and chronic impacts of the climate crisis create problems like poverty, infectious disease, forced migration, and conflict that spread through globalised systems (World Bank, 2021; Bilotta & Botti, 2022). These knock-on impacts affect all nations. COVID-19 served as a wake-up call to these global dynamics and it is no coincidence that health professionals have been active in identifying and responding to the consequences of growing systemic risks to health. But the lessons of the COVID-19 pandemic should not be limited to pandemic risk (WHO, 2021; Al-Mandhari, 2022). Instead, it is imperative that the suffering of frontline nations, including those in Africa, be the core consideration at COP27: in an interconnected world, leaving countries to the mercy of environmental shocks creates instability that has severe consequences for all nations.

The primary focus of climate summits remains to rapidly reduce emissions so that global temperature rises are kept to below 1.5°C. This will limit the harm. But, for Africa and other vulnerable regions, this harm is already severe. Achieving the promised target of providing $100bn of climate finance a year is now globally critical if we are to forestall the systemic risks of leaving societies in crisis. This can be done by ensuring these resources focus on increasing resilience to the existing and inevitable future impacts of the climate crisis, as well as on supporting vulnerable nations to reduce their greenhouse gas emissions: a parity of esteem between adaptation and mitigation. These resources should come through grants, not loans, and be urgently scaled up before the current review period of 2025. They must put health system resilience at the forefront, as the compounding crises caused by the climate crisis often manifest in acute health problems. Financing adaptation will be more cost-effective than relying on disaster relief.

Some progress has been made on adaptation in Africa and around the world, including early warning systems and infrastructure to defend against extremes. But frontline nations are not compensated for impacts from a crisis they did not cause. This is not only unfair, but also drives the spiral of global destabilisation, as nations pour money into responding to disasters, but can no longer afford to pay for greater resilience or to reduce the root problem through emissions reductions. A financing facility for loss and damage must now be introduced, providing additional resources beyond those given for mitigation and adaptation. This must go beyond the failures of COP26 where the suggestion of such a facility was downgraded to “a dialogue” (Evans et al, 2021).

The climate crisis is a product of global inaction, and comes at great cost not only to disproportionately impacted African countries, but also to the whole world. Africa is united with other frontline regions in urging wealthy nations to finally step up, if for no other reason than that the crises in Africa will sooner rather than later spread and engulf all corners of the globe, by which time it may be too late to effectively respond. If so far they have failed to be persuaded by moral arguments, then hopefully their self-interest will now prevail.

Authors: Lukoye Atwoli, Editor-in-Chief, *East African Medical Journal*;

Gregory E. Erhabor, Editor-in-Chief, *West African Journal of Medicine*;

Aiah A. Gbakima, Editor-in-Chief, *Sierra Leone Journal of Biomedical Research*;

Abraham Haileamlak, Editor-in-Chief, *Ethiopian Journal of Health Sciences*;

Jean-Marie Kayembe Ntumba, Chief Editor, *Annales Africaines de Medecine* ;

James Kigera, Editor-in-Chief, *Annals of African Surgery*;

Laurie Laybourn-Langton, University of Exeter;

Bob Mash, Editor-in-Chief, *African Journal of Primary Health Care & Family Medicine*;

Joy Muhia, London School of Medicine and Tropical Hygiene;

Fhumulani Mavis Mulaudzi, Editor-in-Chief, *Curationis*;

David Ofori-Adjei, Editor-in-Chief, *Ghana Medical Journal*;

Friday Okonofua, Editor-in-Chief, *African Journal of Reproductive Health*;

Arash Rashidian, Executive Editor, and Maha El-Adawy, Director of Health Promotion, *Eastern Mediterranean Health Journal*;

Siaka Sidibé, Director of Publication, *Mali Médical*;

Abdelmadjid Snouber, Managing Editor, *Journal de la Faculté de Médecine d'Oran*;

James Tumwine, Editor-in-Chief, *African Health Sciences*;

Mohammad Sahar Yassien, Editor-in-Chief, *Evidence-Based Nursing Research*;

Paul Yonga, Managing Editor, *East African Medical Journal*;

Lilia Zakhama, Editor-in-Chief, *La Tunisie Médicale*;

Chris Zielinski, University of Winchester.

This Comment is being published simultaneously in multiple journals. For the full list of journals see: https://www.bmj.com/content/full-list-authors-and-signatories-climate-emergency-editorial-october-2022

REFERENCES

African Climate Policy Centre (2013). Climate change and Health in Africa: Issues and Options. [Available from: https://archive.uneca.org/sites/default/files/PublicationFiles/policy_brief_12_climate_change_and_health_in_africa_issues_and_options.pdf (accessed 12/9/2022)].

Al-Mandhari A, Al-Yousfi A, Malkawi M, El-Adawy M (2022). "Our planet, our health": saving lives, promoting health and attaining well-being by protecting the planet - the Eastern Mediterranean perspectives. East Mediterr Health J.;28(4):247–248. https://doi.org/10.26719/2022.28.4.247(accessed 26/9/2022) https://doi.org/10.26719/2022.28.4.247 PMid:35545904

Atwoli L, Muhia J, Merali Z (2022). Mental health and climate change in Africa. BJPsych International.:1-4. https://www.cambridge.org/core/journals/bjpsych-international/article/mental-health-and-climate-change-in-africa/65A414598BA1D620F4208A9177EED94B (accessed 26/9/22022). https://doi.org/10.1192/bji.2022.14

Bilotta N, Botti F (2022). Paving the Way for Greener Central Banks. Current Trends and FutureDevelopments around the Globe. Rome: Edizioni Nuova Cultura for Istituto Affari Internazionali (IAI).

Climate Investment Funds (2020).Climate change and Health in Sub-saharan Africa: The Case of Uganda.

Evans M, Munslow B (2021). Climate change, health, and conflict in Africa's arc of instability. Perspectives in Public Health.;141(6):338-41. https://doi.org/10.1177/17579139211058299 PMid:34787038 PMCid:PMC8649415

Evans S, Gabbatiss J, McSweeney R, Chandrasekhar A, Tandon A, Viglione G, Hausfather Z, You X, Goodman J, Hayes S (2021). COP26: Key outcomes agreed at the UN climate talks in Glasgow. Carbon Brief [Internet]. Available from:https://www.carbonbrief.org/cop26-key-outcomes-agreed-at-the-un-climate-talks-in-glasgow/ (accessed 12/9/2022).

Intergovernmental Panel on Climate Change - IPCC (2022). Climate Change 2022: Impacts, Adaptation and Vulnerability. Working Group II Contribution to the IPCC Sixth Assessment Report.

Opoku SK, Leal Filho W, Hubert F, Adejumo O (2021). Climate Change and Health Preparedness in Africa: Analysing Trends in Six African Countries. Int J Environ Res Public Health.; 18(9):4672. https://doi.org/10.3390/ijerph18094672 PMid:33925753 PMCid:PMC8124714

Ritchie H (2019). Who has contributed most to global CO2 emissions?. Our World in Data. https://ourworldindata.org/contributed-most-global-co2 (accessed 12/9/2022).

Stawicki SP, Papadimos TJ, Galwankar SC, Miller AC, Firstenberg MS (2021). Reflections on Climate Change and Public Health in Africa in an Era of Global Pandemic. Contemporary Developments and Perspectives in International Health Security. 2: Intechopen. https://doi.org/10.5772/intechopen.93407

Trisos CH, Adelekan IO, Totin E, Ayanlade A, Efitre J, Gemeda A, Kalaba K, Lennard C, Masao C, Mgaya Y, Ngaruiya G, Olago D, Simpson NP, Zakieldeen S. Contributing Authors:

Antwi-Agyei P, Atteridge A (2022). Africa. In: Climate Change 2022: Impacts, Adaptation, and Vulnerability. [Available from: https://www.ipcc.ch/report/ar6/wg2/ (accessed 26/9/2022)].

United Nations (2022). The Paris Agreement: United Nations; [Available from:https://www.un.org/en/climatechange/paris-agreement (accessed 12/9/2022)].

United Nations Framework Convention on Climate Change -UNFCCC (2020) -Climate change is an increasing threat to Africa. Available from:https://unfccc.int/news/climate-change-is-an-increasing-threat-to-africa (accessed 12/9/2022).

Vulnerable Twenty Group (2020).Climate Vulnerable Economies Loss report. Switzerland. =

World Bank (2021).Climate Change Adaptation and Economic Transformation in Sub-Saharan Africa.

World Health Organisation (2016). Strengthening Health Resilience to Climate Change 2016.

World Health Organisation (2021). COP26 special report on climate change and health: the health argument for climate action, Geneva.

ORIGINAL RESEARCH ARTICLES

Hearing, Speech and Language Outcomes in Children with Cochlear Implants: a Comparison between ADIP Scheme and Self-Financed Scheme

Md Noorain Alam[1]*, Sanjay Kumar Munjal[1], Naresh K Panda[1], N Banumathy[1], Preeti Sharma[1]
1. Post-Graduate Institute of Medical Education and Research (PGIMER), Chandigarh, India

ABSTRACT

Purpose: *Cochlear implants (CIs) are of immense benefit to children with severe to profound hearing impairment. While cochlear implants under the Government of India supported ADIP scheme cost a lot to the public exchequer, parents spend considerable amounts on CI surgery under the self-financed scheme. This study aimed to find and compare outcomes of cochlear implants in children who availed of the ADIP scheme and those who were implanted under a self-financed scheme. The secondary aim was to elicit the views of parents on the challenges their wards faced under the ADIP scheme for cochlear implants.*

Method: *The study focused on twelve children who received cochlear implants under the ADIP scheme and twelve children who received implants under a self-financed scheme at a tertiary care health centre. The baseline for measurement of various outcomes was a minimum of six months post implantation. Cochlear implant outcomes were compared using MAIS/IT-MAIS, SIR, CAP, and ISD tests. Interviews were also conducted with the parents of children who received cochlear implants under the ADIP scheme, for information regarding the challenges they faced.*

Results: *There was a significant difference ($p<.05$) between the two groups in the scores of CAP and reception, speech, and cognition subsections of the ISD scale. The scores of the ADIP group were significantly lower in these domains. The possible reasons might be a lack of funds, not visiting the therapy centre regularly, loss of wages during a visit to the therapy centre, lack of family support, and insufficient time to repeat therapy activities at home. There was*

---

* **Corresponding Author:** Md Noorain Alam, Lecturer, ENT Department, PGIMER, Chandigarh, India. Email:noorain.aslp@gmail.com

no significant difference in age, CI age, and CI usage duration between the two groups.

Conclusion and Implications: *Compared to children implanted under the self-financed scheme, children implanted under the ADIP scheme are significantly lacking in a few domains of communication skills. The efficacy of the ADIP scheme for cochlear implantation can be evaluated and policy change can be advocated based on this study. The study has outlined some modifications to this welfare scheme in order to fill the observed lacunae and widen the scope of its reach.*

Key words: *ADIP scheme, self-financed, outcomes, cochlear implants, challenges*

INTRODUCTION

Hearing impairment is the most prevalent sensory disability (Mathers et al, 2003). More than 466 million people are reported to have moderate to profound hearing loss; many more have mild hearing loss and ear diseases such as otitis media (WHO, 2008). As per the NSSO survey, 291 persons per one lakh population currently suffer from severe to profound hearing loss in India (National Sample Survey Office, 2003). Four in every 1000 children suffer from severe to profound hearing loss, with over 100,000 babies born with hearing deficiency every year in India. Hearing impairment has a significant impact on both children and their families. This is seen in every aspect of their lives, including cognitive, communication, psychosocial, educational, personality development, and financial condition.

Cochlear implantation has been widely used to recover or obtain audition for clients with severe to profound hearing loss. A cochlear implant can effectively stimulate the auditory pathways with electrical pulses, even in cases of severe to profound hearing loss. In the case of children, electrical stimulation of the cochlea can more effectively activate the central auditory pathway, which will provide auditory perception and enable the development of speech perception skills (Miyamoto et al,1995; Geers,1997; Skarzynski et al, 2012).

Cochlear implants are costly devices, with prices ranging from INR 500,000 up to 1,400,000 in India. The cost of surgery and therapy makes the implantation procedure an expensive affair. However, the benefits to communication and other domains of quality of life make it a panacea for severe to profound hearing-impaired children. In India, the central and state governments have started welfare schemes for hearing-impaired children belonging to economically weaker sections of the population.

Assistance to People with Disability for Purchase/ Fitting of Aids and Appliances (the ADIP scheme) - for cochlear implant - is an ambitious welfare scheme for the hearing-impaired population under the Ministry of Social Justice and Welfare, the Government of India (AYJNISHD(D)). The scheme aims to provide cochlear implants to hearing-impaired children from poor economic backgrounds and to support implanted children with auditory verbal therapy (AVT) for two years through empanelled rehabilitation centres. Children under five years of age with severe to profound hearing loss, whose family income is less than INR fifteen thousand per month, and who have no associated disorders are eligible for cochlear implants under the ADIP scheme. To avail of this, parents need to submit documents such as their income certificate, child's birth certificate, hearing handicap certificate, detailed IQ assessment report, audiological assessment reports (Pure tone audiometry, Impedance audiometry, Otoacoustic emission, Auditory brainstem response report, hearing aid benefit report), speech-language assessment report, ENT examination report and radiological report (CT scan and MRI scan to rule out cochlear malformations).

The scheme targets the implantation of 500 children per year, with a ceiling of INR 6 lakhs per unit. The Standing Committee on Social Justice and Empowerment (2017-18) observed in its report that during three initial years (2014 - 2017) only 975 cochlear implant surgeries were conducted across the country, which is far less than the target of 500 implant surgeries per year(Sharma, 2018). Thus, it appears that the ADIP scheme is still struggling to reach out to a large portion of the economically weaker section.

While cochlear implants under the ADIP scheme involve high costs to the public exchequer, parents spend a considerable amount of money on the procedure under the self-financed scheme. Having to pay INR 5 - 14 lakhs for a device, in addition to the costs of investigation, pre-surgery vaccination, hospitalisation, and medicines, places a heavy financial burden on the family. Hence there is a need to study the hearing, speech, and language outcomes in children implanted under the ADIP scheme and compare them with children implanted under the self-financed scheme.

Objective

The present study aimed to find and compare hearing, speech, and language outcomes of children with cochlear implants under the ADIP scheme and those implanted under the self-financed scheme. The secondary aim of the study was to elicit parental views on challenges in the ADIP scheme for their wards with cochlear implants. The efficacy of the welfare scheme can be evaluated, and policy change can be advocated based on the findings of this study.

METHOD

Study Participants

Twelve children implanted under the ADIP scheme and twelve children who received implants under a self-financed scheme at a tertiary care health centre were included in the study. Informed consent was taken from all the participants. The surgeries were performed between 2016 and 2018. Six months post-implantation was taken as a baseline for measurement of outcomes. The parents of children who received cochlear implants under the ADIP scheme were also interviewed to get information regarding the challenges they faced.

Study Tools

Outcome measurement of cochlear implants was done by administering different tools.

Hearing outcomes were assessed using MAIS/IT- MAIS and CAP scale.

- MAIS (Robbins et al, 1991) / Infant-Toddler - Meaningful Auditory Integration Scale or IT-MAIS (Zimmermann-Phillips et al, 2001) - MAIS is a structured interview schedule designed to evaluate the use of conversational listening skills in school-age children. IT-MAIS is the modified MAIS to be used on very young children.
- Categories of Auditory Perception or CAP (Archbold et al, 1995) – This test has 1 to 12 levels to measure auditory skill development. The 12th level is the highest level where the child may use the phone with an unfamiliar speaker.

Speech outcomes were evaluated using the Speech Intelligibility Rating test.

- Speech Intelligibility Rating scale or SIR (Allen et al, 2001) – It categorises the child’s speech intelligibility from 1 to 5 (where 5 is the highest level of intelligibility when the speech is entirely intelligible).

ISD was used to assess speech-language development.

- Integration Scale of Development or ISD (Cochlear) - The scale is helpful to assess speech-language development in six domains: audition, receptive language, expressive language, speech, cognition, and pragmatic skills.

Ethics Approval

All procedures performed with the participants were in keeping with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

RESULTS

The details of children in the ADIP group and self-financed group have been summarised in Table 1 and Table 2.

The ADIP group consisted of 12 children (seven females and five males) with a mean age of 5.64 years (SD 2.29). The mean implant age and implant usage duration were 4.55 years (SD 1.42) and 1.6 years (SD .57). The self-financed group consisted of 12 children (seven females and five males) with a mean age of 5.76 years (SD 1.75). The mean implant age and implant usage duration were 4.57 years (SD 1.71) and 1.32 years (SD 0.67).

Table 1: Details of ADIP Group

S N	Age (yrs)	Gender	Age at implant (yrs)	Implant usage (yrs)	CI company
1	7 .6	F	5.5	2.1	Cochlear
2	7	F	5	2	Cochlear
3	7.83	M	5.83	2.1	Cochlear
4	6 .5	F	4.42	2	Cochlear
5	7 .1	F	5.58	1.5	Cochlear
6	6.1	M	4.58	1.5	Cochlear
7	7	F	5.75	2	Digisonic
8	4	M	3.08	1.9	Digisonic
9	9	F	6	1.75	Cochlear

10	3	M	2.5	0.91	Cochlear
11	3	M	2.8	0.83	Cochlear
12	3.8	F	3.6	0.58	Cochlear

Table 2: Details of Self-Financed Group

SN	Age (yrs)	Gender	Age at implant (yrs)	Implant usage (yrs)	CI company
1	6.41	F	5	1.41	Cochlear
2	7	M	5.67	1.33	Advanced Bionics
3	6	F	5.25	0.75	Medel
4	3.25	M	2.91	2.58	Advanced Bionics
5	5	F	2.25	2	Medel
6	5.92	F	3.9	2.1	Advanced Bionics
7	8	M	7.3	0.58	Advanced Bionics
8	3.5	F	2.84	0.66	Cochlear
9	5.5	M	3.92	1.58	Medel
10	3.75	M	3.16	0.58	Medel
11	5.83	F	5.16	0.75	Advanced Bionics
12	9	F	7.5	1.58	Medel

In the ADIP group, the cochlear implant brands were Cochlear (n=10) and Digisonic (n=2). In the self-financed group, the cochlear implant brands consisted of Cochlear (n=2), Advanced Bionics (AB) (n=5), and Medel (n=5).

A t-test was carried out to determine the mean difference in age, implant age, and implant usage duration between the ADIP group and the self-financed group. As shown in Table 3, there was no significant difference between the two groups on any of these measures.

Table 3: Comparison of Age, Cochlear Implant Age, and Cochlear Implant Usage Duration between the ADIP Group and Self–Financed Group on independent t-test

S N	Name of the Variable	ADIP Group	Self-Financed Group	t-test (p-value)
1	**Age**	5.64(2.29)	5.76(1.75)	0.3(.88)
2	**Age of Implantation**	4.55(1.42)	4.57(1.71)	-0.3(.97)
3	**CI Usage Duration**	1.6(0.57)	1.32(0.67)	1.09(.3)

For statistical analysis, the scores on the ISD scale were taken as a mean of the age range obtained from the scale. The mean scores of different tests in the ADIP group and self-financed group are given in Table 4. When both the groups were compared using an independent t-test, there was a significant difference (p<.05) between the two groups in the scores of CAP and reception, speech, and cognition subsections of the ISD scale. The scores of the ADIP group were significantly lower in these domains. There was no significant difference between the two groups on the domains of MAIS/IT-MAIS and SIR and audition, expressive language, and pragmatics domains of the ISD scale.

To find the difference in CI outcomes between two groups based on age (less than vs. more than five years), gender (male vs. female), cochlear implant age (before vs. after three years), and cochlear implant usage (less than vs. more than one year), independent t-test was carried out. There was no significant difference (p>0.05) between the groups based on gender, age, cochlear implant age, and cochlear implant usage duration. Hence, the difference between the ADIP group and the self-financed group may not be attributed to gender, age, age of implantation, and cochlear implant usage (see Table 4).

Table 4: Comparison of Test Results of Children with Cochlear Implants under ADIP and Self-Financed Scheme on independent t-test

S N	Name of the Test		ADIP Group (Mean)	Self-Financed Group (Mean)	t-test(p-value)
1	**MAIS/IT-MAIS**		28.25	32.42	-1.65(0.11)
2	**SIR**		2.33	2.91	-1.38(0.18)
3	**CAP**		4.25	6.5	**-2.94(0.007)**
4	**ISD**	Audition	15.13	20.25	-1.72(0.1)
5		Reception	14.1	20.38	**-2.14(0.04)**
6		Expression	12.33	17	-1.8(0.08)
7		Speech	12.12	17.4	**-2.2(0.04)**
8		Cognition	24.25	34.63	-3.13(0.005)
9		Pragmatics	24.625	32.75	-1.89(0.072)

Parental Perceptions about Challenges in ADIP Scheme

The parents of children with cochlear implants were asked about the difficulties faced during pre- and post-implant procedures under the ADIP scheme. The challenges have been discussed below.

- **Awareness** – The parents came to know about the ADIP scheme very late, and by the time the applications were accepted and surgeries were performed, the child was over five years of age. Hence the average implant age for children was more than five years. Most parents came to know about the ADIP scheme either through the tertiary centre (n=9) or from the special educators (n=2). One parent came to know about the scheme through a local hospital. Most physicians, including ENTs, are either unaware or reluctant to inform the parents about this central government scheme. Many audiologists do not notify the parents about the scheme as they are not interested in dispensing the costly devices and want their clients to continue using hearing aids. So, even when the hearing aids are not beneficial, parents keep waiting for improvement in their wards' auditory and language skills, and thus precious time is lost.

- **Documentation** – All the parents mentioned that documentation was a tedious job. Getting the disability certificate, IQ certificate, and income certificate took a lot of time and effort. Obtaining an income certificate was difficult for parents working as labourers or in some low-profile jobs. In places like Chandigarh, the officials refused to issue a disability certificate as there was no such provision for these daily wage workers. AYJNISHD (D), Mumbai (the nodal agency supervising the ADIP scheme), needs a detailed psychological report rather than IQ scores. It is not easy to obtain this as most hospitals do not issue detailed IQ reports for young children. Getting a disability certificate at the civil hospitals was difficult due to the lack of human resources at many centres. The parents had to visit many centres to obtain these mandatory documents, and consequently precious time was lost.

- **Delay in Cochlear Implant approval** – After sending all the required documents, there was a gap of 3-6 months to get the approval from the headquarters (AYJNISHD (D), Mumbai). This could be due to a large number of applications from across the country.

- **Hearing Aid trial** - Four parents found it challenging to get the powerful digital hearing aids for the three-month trial period. Most of them used body-level hearing aids before cochlear implants. There is no provision for dispensing hearing aids and batteries to poor clients during hearing aid trials under the ADIP scheme for cochlear implants.

- **Post-implant Rehabilitation** – Seven implantees found it challenging to take the AVT therapy from qualified audiologists, mainly due to the distance to the therapy centre from their homes. One implantee could not visit the therapy centre regularly due to a lack of family support and financial issues. One family relocated to stay close to the therapy centre.

- **Availability of Accessories and Servicing –** Some parents had difficulty procuring cochlear implants accessories, like batteries and cables. For Digisonic instruments, there were no local dealers for accessories. There was also a concern about the accessory cost and recurrent cost of batteries. There was no backup for these expenses. The parents felt that the government should provide financial assistance to meet these costs as well.

- **Cochlear Implant Company Support –** Initially, it was difficult to map the processor for the first Digisonic implanted child in this study, as she would not cooperate. It took about three months to find the child's behaviour threshold. The mapping centre could not get the necessary support from the company.

- **Non-availability of Habilitation Programme in Hindi –** Parents reported that the respective cochlear implant companies failed to provide adequate AVT materials and troubleshooting methodology in the Hindi language, which could be used as a guide at home.

DISCUSSION

The study results suggested that auditory and speech-language skills had developed in cochlear implanted children in both the ADIP and self-financed groups. There are comparable studies that propose a growth in receptive vocabulary in CI children right after the initial fit or with increasing hearing age (Robbins, 2004). Schramm et al (2010) found that progress in hearing and language development assessed by questionnaires in 60% of CI children was nearly comparable to the development of their normal-hearing peers. Different factors affect the outcomes in CI children. This includes the hearing loss duration, hearing aid use, residual hearing, pre-operative speech recognition, implant age, parent support, speech therapy, etc., (Rubinstein et al, 1999; Green et al, 2007; Carlson et al, 2011; Lazard et al, 2012; Blamey et al, 2013; Holden et al, 2013; Plant et al, 2016). The implant brand, number of electrodes inside the cochlea (Gifford et al, 2013), and residual hearing preservation (Aschendorff et al, 2007; Skinner et al, 2007; Finley et al, 2008; Wanna et al, 2014) are device and surgery-related factors.

Significant differences were observed under the domains of audition, reception, speech, cognition, pragmatics skills, and CAP test, between self-financed implanted children and children implanted under the ADIP scheme. Poor scores in the ADIP group may be attributed to scarce financial resources (reducing to and from visits to the intervention centre), lack of parental education, and lack of awareness, leading to less stimulation and support at home. Parents under the self-financed scheme are more motivated to improve the communication abilities of their implanted wards. They attend the therapy sessions regularly and devote extra time to repeat the therapy activities at home. Thus their children with implants get more support from the family.

The caregivers who availed of the ADIP scheme perceived the following challenges: lack of awareness, delay in cochlear implant approval, unavailability of enough AVT centres, lack of finance for hearing aid trial, etc. Post-implant service is also considered critical. It is the responsibility of the implementing agency to take care of the service and repair of these instruments. All the parents were satisfied with the ADIP scheme and even suggested spreading more awareness among the masses. They also mentioned empanelling more AVT centres with qualified audiologists, which would help the children to attend regular therapy sessions. Some parents suggested prioritising the post-implant service. Also, habilitation material in the Hindi language was required.

The ADIP scheme has been introduced keeping in mind the majority of the population in India, i.e., the lower-middle and low-income group. The impact of this scheme is directly linked to general awareness about the programme among the masses. The ADIP programme has been widely accepted, and professionals and parents have duly recognised its benefits across the country.

There is scope for improvement in the ADIP scheme, as summarised below.

1. **The maximum age criteria -** It should be raised from 5 to at least 7 years. Children with hearing impairment are identified late due to the non-

availability of hearing care services in far-off places, especially in rural areas. By the time they are referred to an ADIP recognised centre, it is already late.

2. **Duration of rehabilitation services** - Provision for AVT is limited to two years under the scheme. However, it has been noticed that many clients either miss the sessions due to various reasons or need support beyond two years. Hence the free AVT sessions may be allowed for at least three years, with frequency increased from three to five sessions per week.

3. **Assistance for accessories** – These families need support beyond the standard warranty period provided by the cochlear implant companies. The accessories, including the rechargeable batteries and cables, need an extended warranty of at least five years. There should also be a provision for the replacement and repair of parts of implants and batteries free of cost.

4. **Candidacy for bilateral implantation** – Sometimes, the family can get the first implant under different schemes like Sarva Shiksha Abhiyan, MP fund, etc. However, they are not candidates under the ADIP scheme for the second implantation. This needs to be revised.

5. **Cochlear Implants for children with additional disabilities –** Though cochlear implants have a guarded prognosis in cases of cochlear anomalies, the children still do better than those with other modes of amplification and should be included in the candidacy criteria under the ADIP scheme.

CONCLUSION

The ADIP scheme for cochlear implants is an appreciable advance that has allowed hearing-impaired children from a lower socioeconomic background to develop auditory, speech, and language skills and join the mainstream. However, compared with children who received implants under the self-financed scheme, children with implants under the ADIP scheme are significantly lacking in a few communication skills. The lacunae in this ambitious welfare scheme need to be dealt with so that the large hearing-impaired population in India may benefit.

ACKNOWLEDGEMENT

The authors declare that there is no conflict of interest.

REFERENCES

Allen, C., Nikolopoulos, T. P., Dyar, D., & O'Donoghue, G. M. (2001). Reliability of a rating scale for measuring speech intelligibility after pediatric cochlear implantation. *Otology & Neurotology*, *22*(5), 631-633. https://doi.org/10.1097/00129492-200109000-00012, PMid:11568670

Archbold, S., Lutman, M. E., & Marshall, D. H. (1995). Categories of auditory performance. *The Annals of otology, rhinology & laryngology. Supplement*, *166*, 312-314. PMid:7668685

Aschendorff, A., Kromeier, J., Klenzner, T., & Laszig, R. (2007). Quality control after insertion of the nucleus contour and contour advance electrode in adults. *Ear and hearing*, *28*(2), 75S-79S. https://doi.org/10.1097/AUD.0b013e318031542e, PMid:17496653

Cochlear Implant under ADIP Scheme of Government of India. Retrieved 21/12/2009 from http://www.adipcochlearimplant.in/ADIP-scheme.aspx.

Blamey, P., Artieres, F., Başkent, D., Bergeron, F., Beynon, A., Burke, E., ... & Lazard, D. S. (2013). Factors affecting auditory performance of post-linguistically deaf adults using cochlear implants: an update with 2251 patients. *Audiology and Neurotology*, *18*(1), 36-47. https://doi.org/10.1159/000343189, PMid:23095305

Carlson, M. L., Driscoll, C. L., Gifford, R. H., Service, G. J., Tombers, N. M., Hughes-Borst, B. J., ... & Beatty, C. W. (2011). Implications of minimizing trauma during conventional cochlear implantation. *Otology & neurotology: official publication of the American Otological Society, American Neurotology Society [and] European Academy of Otology and Neurotology*, *32*(6), 962. https://doi.org/10.1097/MAO.0b013e3182204526, PMid:21659922 PMCid:PMC4127076

Cochlear. Integrated Scales of Development. Retrieved 23/12/2019 from http://www.cochlear.com/home/sipport/rehabilitation-resources/early-intervention/scales-of-developemnt-isd.

Finley, C. C., & Skinner, M. W. (2008). Role of electrode placement as a contributor to variability in cochlear implant outcomes. *Otology & neurotology: official publication of the American Otological Society, American Neurotology Society [and] European Academy of Otology and Neurotology*, *29*(7), 920. https://doi.org/10.1097/MAO.0b013e318184f492, PMid:18667935 PMCid:PMC2663852

Geers, A. E., & From the Central Institute for the Deaf, S. (1997). Comparing implants with hearing aids in profoundly deaf children. *Otolaryngology-Head and Neck Surgery*, *117*(3), 150-154. https://doi.org/10.1016/S0194-5998(97)70167-0

Gifford, R. H., Dorman, M. F., Skarzynski, H., Lorens, A., Polak, M., Driscoll, C. L., ... & Buchman, C. A. (2013). Cochlear implantation with hearing preservation yields significant benefit for speech recognition in complex listening environments. *Ear and hearing*, *34*(4), 413. https://doi.org/10.1097/AUD.0b013e31827e8163, PMid:23446225 PMCid:PMC3742689.

Green, K. M., Bhatt, Y. M., Mawman, D. J., O'Driscoll, M. P., Saeed, S. R., Ramsden, R. T., & Green, M. W. (2007). Predictors of audiological outcome following cochlear implantation in adults. *Cochlear implants international*, *8*(1), 1-11. https://doi.org/10.1179/cim.2007.8.1.1, PMid:17479968

Holden, L. K., Finley, C. C., Firszt, J. B., Holden, T. A., Brenner, C., Potts, L. G., ... & Skinner, M. W. (2013). Factors affecting open-set word recognition in adults with cochlear implants. *Ear and hearing*, *34*(3), 342. https://doi.org/10.1097/AUD.0b013e3182741aa7, PMid:23348845 PMCid:PMC3636188

Lazard, D. S., Vincent, C., Venail, F., Van de Heyning, P., Truy, E., Sterkers, O., ... & Blamey, P. J. (2012). Pre-, per-and postoperative factors affecting performance of postlinguistically deaf adults using cochlear implants: a new conceptual model over time. *PloS one*, *7*(11), e48739. https://doi.org/10.1371/journal.pone.0048739, PMid:23152797 PMCid:PMC3494723

Mathers, C., Smith, A., & Concha, M. (2000). Global burden of hearing loss in the year 2000. *Global burden of Disease*, *18*(4), 1-30.

Miyamoto, R. T., Kirk, K. I., Todd, S. L., Robbins, A. M., & Osberger, M. J. (1995). Speech perception skills of children with multichannel cochlear implants or hearing aids. *The Annals of otology, rhinology & laryngology. Supplement*, *166*, 334-337.

PMid:7668695

National Sample Survey Organisation. (2003). *Disabled Persons in India: NSS 58th Round, July-December 2002* (No. 485). National Sample Survey Organisation, Ministry of Statistics and Programme Implementation, Government of India.

Plant, K., McDermott, H., Van Hoesel, R., Dawson, P., & Cowan, R. (2016). Factors predicting postoperative unilateral and bilateral speech recognition in adult cochlear implant recipients with acoustic hearing. *Ear and Hearing*, *37*(2), 153-163. https://doi.org/10.1097/AUD.0000000000000233, PMid:26462170

Robbins, A. M., Renshaw, J. J., & Berry, S. W. (1991). Evaluating meaningful auditory integration in profoundly hearing-impaired children. *The American journal of otology*, *12*, 144-150. PMID: 2069175

Robbins, A. M., Koch, D. B., Osberger, M. J., Zimmerman-Phillips, S., & Kishon-Rabin, L. (2004). Effect of age at cochlear implantation on auditory skill development in infants and toddlers. *Archives of Otolaryngology–Head & Neck Surgery*, *130*(5), 570-574. https://doi.org/10.1001/archotol.130.5.570, PMid:15148178

Rubinstein, J. T., Parkinson, W. S., Tyler, R. S., & Gantz, B. J. (1999). Residual speech recognition and cochlear implant performance: effects of implantation criteria. *The American journal of otology*, *20*(4), 445-452. PMid:10431885

Schramm, B., Bohnert, A., & Keilmann, A. (2010). Auditory, speech and language development in young children with cochlear implants compared with children with normal hearing. *International Journal of Pediatric Otorhinolaryngology*, *74*(7), 812-819. https://doi.org/10.1016/j.ijporl.2010.04.008, PMid:20452685

Sharma NC (2018). Govt missed target of conducting 500 free cochlear implant surgeries, says report. Mint. Retrieved 21/11/2019 from https://www.livemint.com/Politics/qDxrmEooPV9zWhiDq92h0L/Govt-missed-target-of-conducting-500-free-cochlear-implant-s.html.

Skarzynski, H., Lorens, A., Matusiak, M., Porowski, M., Skarzynski, P. H., & James, C. J. (2012). Partial deafness treatment with the nucleus straight research array cochlear implant. *Audiology and Neurotology*, *17*(2), 82-91. https://doi.org/10.1159/000329366, PMid:21846981

Skinner, M. W., Holden, T. A., Whiting, B. R., Voie, A. H., Brunsden, B., Neely, J. G., ... & Finley, C. C. (2007). In vivo estimates of the position of advanced bionics electrode arrays in the human cochlea. *Annals of Otology, Rhinology & Laryngology*, *116*(4_suppl), 2-24. https://doi.org/10.1177/000348940711600401

Wanna, G. B., Noble, J. H., Carlson, M. L., Gifford, R. H., Dietrich, M. S., Haynes, D. S., ... & Labadie, R. F. (2014). Impact of electrode design and surgical approach on scalar location and cochlear implant outcomes. *The Laryngoscope*, *124*(S6), S1-S7. https://doi.org/10.1002/lary.24728, PMid:24764083 PMCid:PMC4209201

World Health Organization. (2008). *The global burden of disease: 2004 update*. World Health Organization.

Zimmerman-Phillips, S., Robbins, A. M., & Osberger, M. J. (2000). Assessing cochlear implant benefit in very young children. *The Annals of Otology, Rhinology & Laryngology*, *109*(12), 42. https://doi.org/10.1177/0003489400109S1217 PMid:11140998

Resilience and Coping by Parents of Children with Intellectual Disability in Kerala, South India

Anugraha Merin Rajan[1]*, J Romate[2]

1. Central University of Punjab, India
2. Central University of Karnataka, India

ABSTRACT

Purpose: *This study examined the relationship between the resilience and coping mechanisms of parents of children with intellectual disability.*

Method: *Study participants were recruited from special schools and neighbourhood groups of parents of children with special needs in Kerala, a southern state of India. Around 121 parents completed the Connor-Davidson Resilience Scale and Coping Strategies Screen. The correlational analysis revealed a significant relationship between their coping strategies and resilience.*

Results: *Problem focussed coping strategies such as problem-solving skills, taking professional assistance, seeking information about managing the condition, taking time to discuss the ways of handling child's condition with the family members/significant others and having recreational activities improved parental resilience. Whereas, emotion focused coping strategies for example, reliance on religious leaders for emotional support, weeping, blaming fate and doing nothing decreased their resilience. Rehabilitation professionals may plan interventions to expand problem focused coping skills so as to improve their resilience*

Conclusion: *The findings have specific applications in developing interventions for parents of children with intellectual disability.*

Key words: *resilience, problem-focussed coping, emotion-focussed coping, parents, children with intellectual disability*

INTRODUCTION

Caring for a child with intellectual disability is a demanding task that requires lifelong commitment (Grant et al, 2007). Parents, who primarily take up the

---

* **Corresponding Author:** Anugraha Merin Rajan, Central University of Punjab, India. Email:anugrahamerin@gmail.com

role of caregivers, often go through a period of emotional upheaval following the diagnosis of the condition (Heiman, 2002; Kandel & Merrick, 2003; Chang & McConkey, 2008; Bruce & Wilmshurst, 2016). They often struggle with the demands of the child's condition, additional financial needs, worry about the child's future, poorly coordinated services, meeting the needs of other family members, spending quality time with them, stigmatising experiences, and lack of support. These prolonged caregiving challenges may also restrict their careers as well as social life, and take a toll on their physical and mental health (Peshawaria et al, 1995; Heiman, 2002; Blacher & Mink, 2004; Pilusa, 2006; Murphy et al, 2007; Reichmann et al, 2007; Gohel et al, 2011; Kishore, 2011; Seltzer et al, 2011; Chadwick et al, 2013).

Apart from these challenges, parents mention several benefits associated with caregiving, mostly in terms of personal growth (Peshawaria et al, 1995; Larson, 1998; Scorgie & Sobsey, 2000; Ferguson, 2002; Hastings & Taunt, 2002; Heiman, 2002; Landsman, 2003; Grant, 2007; Green, 2007; Murphy et al, 2007; Reichmann et al, 2007; Chang & McConkey, 2008; Ryan & Runswick-Cole, 2008; Gohel et al, 2011; Kishore, 2011; Knight, 2013; Beighton & Wills, 2017), perspectival changes(Murphy et al, 2007; Goodley & McLaughlin, 2008), and improved support systems (McConnell et al, 2015). A few examples of such benefits are learning professional skills in caregiving (Chang & McConkey, 2008), becoming more accommodating to disability (Murphy et al, 2007; Goodley & McLaughlin, 2008), taking up advocacy initiatives (Chadwick et al, 2013), and choosing a career in the disability or health sector (Murphy et al, 2007; Beighton & Wills, 2017).

Caregiving is thus associated with both positive and negative experiences. However, in the field of intellectual disability the negative aspects received wider research attention as the studies were mostly guided by the medical model of disability (Ferguson, 2000, 2002; Ryan & Runswick-Cole 2008; Knight, 2013). There has recently been a paradigm shift in the research focus towards identifying parental strengths in caregiving, and thus studies on their resilience have started emerging (Knight, 2013). Such studies better explain how parents attempt to thrive in the context of caring for a child with intellectual disability.

Researchers conceptualised resilience as an outcome or a process (Olsson et al, 2003; Kolar, 2011; Lee et al, 2012; Lee et al, 2013). The former approach considered it as the ability to maintain functionality in the midst of adverse life events. However, the latter approach emphasised the dynamic process of positive adaptation that involves the interplay of risk and protective elements operating from various levels despite adversity (Luthar & Cicchetti, 2000; Luthar et al, 2000). The latter approach is preferred in social science research as it gives importance to personal, familial and contextual influences on resilience (Kolar, 2011).

In the field of intellectual disability, Olsson (2008) proposed a resilience model for parents, emphasising the interplay of child and disability-related intrapersonal and socio-ecological risk as well as protective factors. According to Olsson, both risk and protective factors need to be simultaneously studied. However, the existing studies mostly highlighted the role of intrapersonal or familial protective factors such as hope (Lloyd & Hastings, 2009), parent-child relationship, well-being (Gerstein et al, 2009), meaning making (Gardner & Harmon, 2002; Knestrict & Kuchey, 2009; Breitkreuz et al, 2014), benefit finding (Gardner & Harmon, 2002; Bayat, 2007; Knestrict & Kuchey, 2009; Breitkreuz et al, 2014), families' ability to have a rhythm (Knestrict & Kuchey, 2009), their communication skills, knowledge of disability, acceptance of the child with disability (Greeff & Walt, 2010), and spirituality (Bayat, 2007; Greeff & Walt, 2010).The emphasis is seldom on the risk factors except for a few elements such as problem behaviours of children (Lloyd & Hastings, 2009; McConnell et al,2014), restrictions in social life, lack of support (Breitkreuz et al, 2014) and financial difficulties (Knestrict & Kuchey, 2009; Breitkreuz et al, 2014; McConnell et al, 2014). In addition to these risk and protective factors, Olsson's model considered coping strategy as another intrapersonal factor of resilience. According to Olsson, emotion-focussed coping can act as a risk whereas problem-focussed coping is a protective element. There is limited research on this population that shows the relationship of these coping strategies with resilience.

Emotion-focussed coping involves the attempts to manage or reduce the emotional consequences of a stressful situation (Lazarus & Folkman, 1984). Kishore (2011) referred to these strategies as negative coping as they do not solve the problem directly. They are helpful in the initial exposure to the stressful situations that are unchangeable or beyond one's control (Lazarus & Folkman, 1984; Lazarus, 1993; Ylvén et al, 2006). Since disability is this type of a situation, this kind of coping is likely (Essex et al, 1999; Olsson, 2008; Mirsaleh et al, 2011). However, long-term reliance on this leads to psychological problems (Lazarus, 1993). Similarly, among parents of children with intellectual disability, studies revealed that the increased use of these strategies is associated with less positive parental outcomes such as higher levels of subjective burden (Kim et al,2003), depression (Dunn et al,2001; Kim et al, 2003; van der Veek et al, 2009) and stress (Seltzer et al,1995), poor mental health (McConkey et al,2008), spousal relationship issues (Dunn et al, 2001), social isolation (Dunn et al, 2001), and poor parent-child relationships (Kim et al, 2003). Furthermore, such dependency affected their mood (Pottie & Ingram, 2008) and sense of competence (Judge, 1998).

On the other hand, problem-focussed coping refers to the efforts to alter or prevent a stressful situation or reduce its effects (Lazarus & Folkman,1984). They help the person under stress to manage the situation by confronting the problem, generating strategies and mobilising resources, and hence Kishore (2011) referred to them as positive coping. They are effective in those situations that are perceived as changeable or controllable (Folkman, 1984; Lazarus, 1999; Ylvén et al, 2006). Parental use of these strategies resulted in more positive outcomes such as greater well-being (Seltzer et al, 1995), family strengths (Judge, 1998), family adaptation (Greeff & Walt, 2010), mental health (Bourke-Taylor et al, 2012; Zablotsky et al, 2013) and positive mood (Pottie & Ingram, 2008). They improved the quality of their relationship with their child (Kim et al, 2003) and lowered their levels of depression (Dunn et al, 2001; Kim et al, 2003), burden (Kim et al, 2003), stress (Koydemir-Özden & Tosun, 2010; Lyons et al,2010; John, 2012; Zablotsky et al, 2013), spousal relationship problems (Dunn et al, 2001), and negative mood (Pottie & Ingram, 2008).

Peer and Hillman (2014), in their review of the research on parental stress and adaptation, suggested that the reliance on problem-focused strategies protected parents from the emotional turmoil associated with caregiving and had the potential to promote resilience. Similarly, Grant et al (2007) in their parental resilience model proposed that these methods helped them to maintain control over caregiving demands and could influence the resilience process. The general resilience literature (Patterson, 2002; Rutter, 2006, 2007, 2013; Walsh, 2003, 2008; Wu et al, 2013) also highlighted the protective nature of active coping methods.

Objective

The present study aimed to examine the relationship between parents' resilience and their coping strategies, using a correlational design. Based on the above findings it was hypothesised that when parents rely on emotion-focused coping strategies they experience lower resilience, and when they rely on problem-focused coping strategies they experience higher resilience. More knowledge about this link can guide the rehabilitation professionals in formulating intervention plans to expand parental coping strategies and thus enhance their resilience.

METHOD

Study Participants

The study participants were recruited from Kerala, a southern state of India, through two sources: (a) special schools and (b) neighbourhood groups of parents of children with special needs. From these two sources, 121 parents met the inclusion criteria for this study.

Included were:

Parents whose child, 5 years of age or older, had been diagnosed with intellectual disability at least two years earlier.

Excluded were:

Single/ parents, stepparents, parents with mental illness, and parents with intellectual disability, as previous studies reported that these factors affect the resilience process (Luthar, 1991; Winders, 2014).

The mean age of the parents was 43.18 years (SD: 6.92, range: 30-60). There were 54 fathers and 67 mothers. From 17 families, both parents were participants, whereas from each of the 87 families only one parent participated. With regard to education, 59% had finished high school, 27% had completed intermediate, and 14% had some college-level education. The mean number of years that they had lived with the child since the diagnosis of the condition was 12.07 years (SD: 5.15, range: 2-29). Among the parents, 88% resided in rural areas. With regard to their monthly income, 75% were earning up to Rs. 5000, 7% were earning between Rs. 5001-10,000, and 17% were earning more than Rs. 10,000.

The mean age of the children with intellectual disability was 14.01 years (SD: 5.14, range: 5-32).Among them, there were 72 males and 49 females. Regarding the severity of disability, 46% had mild, 31% had moderate, 18% had severe, and 5% had profound intellectual disability.

Measures

Connor-Davidson Resilience Scale (CD-RISC)

The Connor-Davidson Resilience Scale (CD-RISC), a five-point rating scale, was used to assess the resilience of the participants. The total score ranges from ‘0’ to ‘100’, and a higher score indicates greater resilience. The scale has an internal consistency of 0.89 and test-retest reliability of 0.87. The convergent validity was found by correlating the scale scores with hardiness, perceived stress, stress vulnerability, and social support measures. The CD-RISC had a positive correlation with hardiness and social support, but an inverse correlation with stress and stress vulnerability (Connor & Davidson, 2003).

Coping Strategies Screen (CSS)

The Coping Strategies Screen (CSS), a three-point rating scale consisting of 14 items, assessed the coping strategies commonly used by parents in the context of their child’s disability. Among the 14 items, 5 indicate problem-focused coping strategies while the remaining items indicate emotion-focused coping strategies. The scale generates scores for both types of strategies separately, by providing a total score for items in each category. The inter-rater reliability of the scale was 0.95. The content and face validity were established by consensus among the professionals working in the field of intellectual disability (Kishore, 2011; Kishore et al, 2004).

Procedure

The parents were requested to bring their child’s medical records and disability certificate (a document issued by the district medical board that provides information about the child’s disability and is essential for availing of government schemes and benefits), in order to collect information about the child’s diagnosis, associated difficulties, and level of severity of disability. They were also asked to bring their own medical records to rule out any history of terminal/mental illness or intellectual disability. They filled in the demographic information in the demographic data sheet. The CD-RISC and CSS were administered to them in their native language, and they marked their responses in the space provided.

Data Analysis

The IBM SPSS Statistics Version 21.0.0 was used to analyse the data. Descriptive statistics were calculated for the study variables. Pearson correlation coefficients were used to assess the relationship between resilience and coping strategies.

Ethics Approval

Ethical approval was given by the Central University of Karnataka.

Parents were met individually and informed about the purpose of the study. They were included after they gave their consent and were assured of confidentiality.

RESULTS

Table 1 gives the descriptive statistics of the study variables. Among the emotion-focused coping strategies, approaching religious leaders or gurus for emotional and moral support (74%) was the most used strategy. The least used emotion-focused strategies were blaming fate and doing nothing (43%) and venting negative feelings on the child (43%). On the other hand, the most preferred problem-focused coping strategy was approaching professionals for guidance and help (93%), whereas seeking technical information regarding the management of the problems (50%) was the least preferred problem-focused strategy.

Table 1: Descriptive Statistics of Study Variables

Variable	n	%	M	SD
Emotion-focused Coping			6.32	2.93
Approaching religious leaders/gurus for emotional and moral support	90	74.38	.93	.66
Blaming fate and doing nothing	52	42.98	.55	.71
Crying/Weeping	77	63.64	.76	.66
Indulging more in domestic or professional activities to divert attention from the problem	82	67.77	.83	.67
Neglecting child with disability for a while or till feeling better	56	46.28	.47	.52
Neglecting other duties and focusing on child only	80	66.12	.94	.79
Performing religious rituals to divert attention or to feel better	77	63.64	.83	.72
Venting negative feelings on child	52	42.98	.45	.53
Venting negative feelings on spouse	63	52.07	.56	.58
Problem-focused Coping			5.21	2.16
Approaching professionals for guidance and help	113	93.39	1.45	.62
Discussing with others or family members how to solve the problem	104	85.95	1.12	.63

Taking up recreational activities	86	71.07	.86	.65
Seeking more technical information regarding management of the problem	60	49.58	.58	.64
Trying to solve the problem myself by analysing the situation	98	80.99	1.20	.74
Resilience			65.15	15.74

Note: n = 121

Table 2 presents the findings of correlational analysis of predictor variables with resilience. The results revealed a significant inverse correlation between resilience and emotion-focused coping. Among the strategies, approaching religious leaders for emotional and moral support, blaming fate, crying, diverting attention using domestic or professional activities, neglecting the child with disability, and venting negative feelings on child and on spouse decreased their resilience. It also indicated a significant positive relationship of resilience and problem- focused coping. The strategy-wise analysis revealed the same too.

Table 2: Pearson Correlation Coefficients of Resilience and Coping

Variable	*r*	*p*
Emotion-focused Coping	-.43**	< .001
Approaching religious leaders/gurus for emotional and moral support	-.26**	0.002
Blaming fate and doing nothing	-.39**	< .001
Crying/Weeping	-.39**	< .001
Indulging more in domestic or professional activities to divert attention from the problem	-.17*	0.028
Neglecting child with disability for a while or till feeling better	-.27**	0.002
Neglecting other duties and focusing on child only	.11	0.126
Performing religious rituals to divert attention or to feel better	-.11	0.118
Venting negative feelings on child	-.32**	< .001
Venting negative feelings on spouse	-.23**	0.005
Problem-focused Coping	.59**	< .001
Approaching professionals for guidance and help	.31**	< .001
Discussing with others or family members how to solve the problem	.34**	< .001
Taking up recreational activities	.47**	< .001

Seeking more technical information regarding management of the problem	$.35^{**}$	$< .001$
Trying to solve the problem myself by analysing the situation	$.47^{**}$	$< .001$

$^{*}p < .05$, $^{**}p < .01$

DISCUSSION

Parents experienced lower levels of resilience when they relied more on emotion-focused coping strategies. This supports Olsson's model and the findings of parental stress and well-being literature (Seltzer et al, 1995; Kim et al, 2003; McConkey et al, 2008). According to Lazarus and Folkman (1984), when a life event is perceived as unalterable, individuals tend to develop learned helplessness, become passive and restricted in coping skills. Subsequently, they start using a greater number of emotion-focused coping strategies (Luthar, 1991; Wu et al, 2013). Rutter (1999) stated that when a person relies more on maladaptive ways of coping following an adversity, it is more likely that negative chain reactions will persist. The presence of such reactions over a longer period of time may influence him/her to carry forward the ill effects of adversity, and makes him/her more vulnerable to further adversities. In the context of parents as well, these strategies delay their active response towards the stress or burden associated with raising a child with disability and affects their competence and sense of control (Judge, 1998). Thus, when parents lack mastery over the situation, they tend to get entangled with the challenges of caregiving and experience low resilience (Grant et al, 2007; Breitkreuz et al, 2014). In the present study, the emotion-focused strategies such as approaching religious leaders for support, blaming fate and doing nothing, crying, diverting attention using domestic or professional activities, neglecting the child with disability for some time or till they feel better, and venting negative feelings on child and on spouse decreased their resilience. There is previous evidence that the strategies like self-blaming and detaching oneself from the stressful situation by engaging in other activities affected their mood, made them more depressive, and lowered their sense of commitment and control (Judge, 1998; Pottie & Ingram, 2008; van der Veek et al, 2009).

The reliance on problem-focused coping methods improved parental resilience. This confirms Olsson's model and the findings of general resilience literature (Patterson, 2002; Rutter, 2006, 2007, 2013; Walsh, 2003, 2008; Wu et al, 2013). The strategies that facilitated parental resilience were: approaching professionals for guidance, seeking information about the child's condition and its management, discussing with others or family members about how to deal with the problem, taking up recreational or pleasurable activities, and utilising problem-solving skills. These proactive methods helped them to gain control over demands of caregiving, allocate time to care for themselves in the midst of caregiving responsibilities, and find new ways to grow out of difficulties (Judge, 1998; Gardner & Harmon, 2002; Heiman, 2002; Chang & McConkey, 2008; Pottie & Ingram, 2008; Greeff & Walt, 2010; Koydemir-Özden & Tosun, 2010; Bourke-Taylor et al, 2012). Achieving control over demands further helps them to re-evaluate their caregiving skills, maintain a considerable degree of stability and predictability in daily caregiving, and prevents them from feeling trapped in caregiving responsibilities (Grant et al, 2007). Thus, when they move from crisis reactive mode towards a proactive mode of functioning, they become more resilient (Walsh, 2003, 2008).

Parents used both problem-focused and emotion-focused coping methods to deal with their child's disability. This corresponds with the previous finding that the problem-focused approaches they relied on did not prevent them from using emotion-focused approaches. As disability is an unchangeable situation, they tend to use both methods in spite of knowing that the latter methods are less helpful (Essex et al, 1999; Olsson, 2008; Kishore, 2011).

The findings imply that parental problem-focused coping can function as a protective mechanism in the context of resilience, whereas emotion-focused coping can be a risk element. As parents tend to rely on both coping strategies, professionals need to follow a flexible approach while assisting them. They can place more emphasis on adaptive methods such as teaching problem-solving skills, receiving professional guidance, seeking information about the management of the condition, discussing with family members or significant others about various ways to deal with the problems at hand, and taking up recreational activities. Methods such as seeking emotional and moral support from religious leaders, blaming fate and doing nothing, crying, diverting attention using domestic or professional activities, neglecting the child with disability for some time or till they feel better, and venting negative feelings on child and on spouse, need not be encouraged though parents may indulge in them at times.

Study Limitations

Majority of the parents had some school education, earned a low income, and were residing in rural areas. These factors could influence their access to various resources or services to deal with their child's disability. Hence, future studies need to select a representative sample by considering these variables. The present study recruited parents from special schools and parent groups. These sources provide access to various services and a platform for similar parents to meet up and discuss their issues. This has the potential to influence their coping behaviours. Future research can consider including a group of parents who do not receive such services. The data can be enriched by adding a qualitative component, for example in-depth interviews, and thus explore the phenomena of resilience from a mixed method approach.

CONCLUSION

Parents used both the problem-focused and emotion-focused coping methods to deal with their child's disability. These methods influenced their resilience process. Problem-focused coping contributed to their resilience whereas emotion-focused coping lowered their resilience.

REFERENCES

Bayat, M. (2007). Evidence of resilience in families of children with autism. *Journal of Intellectual Disability Research*, *51*(9), 702–714. https://doi.org/10.1111/j.1365-2788.2007.00960.x, PMid:17845239

Beighton, C., & Wills, J. (2017). Are parents identifying positive aspects to parenting their child with an intellectual disability or are they just coping? A qualitative exploration. *Journal of Intellectual Disabilities, 21* (4), 325-345. https://doi.org/10.1177/1744629516656073, PMid:27352854 PMCid:PMC5703033

Blacher, J., & Mink, I. T. (2004) Interviewing family members & care providers: concepts, methodology & cultures. In E. Emerson, C. Hatton, T. Thompson, & T. R. Parmenter (Eds.), *The International Handbook of Applied Research in Intellectual Disabilities* (pp. 133–153). Wiley. https://doi.org/10.1002/9780470713198.ch6

Bourke-Taylor, H., Pallant, J. F., Law, M., & Howie, L. (2012). Predicting mental health among mothers of school-aged children with developmental disabilities: The relative contribution of child, maternal and environmental factors. *Research in Developmental Disabilities*, *33*(6), 1732–1740. https://doi.org/10.1016/j.ridd.2012.04.011, PMid:22699247

Breitkreuz, R., Wunderli, L., Savage, A., & McConnell, D. (2014). Rethinking resilience in families of children with disabilities: a socioecological approach. *Community, Work & Family*, *17*(3), 346–365. https://doi.org/10.1080/13668803.2014.893228

Bruce, A. W., & Wilmshurst, L. (2016). *Essentials of intellectual disability assessment and identification*. Wiley.

Chadwick, D. D., Mannan, H., Garcia Iriarte, E., McConkey, R., O'Brien, P., Finlay, F., … Harrington, G. (2013). Family Voices: Life for Family Carers of People with Intellectual Disabilities in Ireland. *Journal of Applied Research in Intellectual Disabilities, 26*(2), 119–132. https://doi.org/10.1111/jar.12003, PMid:23225734

Chang, M.Y., & McConkey, R. (2008). The perceptions and experiences of Taiwanese parents who have children with an intellectual disability. *International Journal of Disability, Development and Education, 55*(1), 27–41.https://doi.org/10.1080/10349120701827961

Connor, K. M., & Davidson, J. R. T. (2003). Development of a new resilience scale: The Connor-Davidson Resilience Scale (CD-RISC). *Depression and Anxiety, 18*(2), 76–82. https://doi.org/10.1002/da.10113, PMid:12964174

Dunn, M. E., Burbine, T., Bowers, C. A., & Tantleff-Dunn, S. (2001). Moderators of stress in parents of children with autism. *Community Mental Health Journal, 37*(1), 39–52. https://doi.org/10.1023/A:1026592305436, PMid:11300666

Essex, E. L., Seltzer, M. M., & Krauss, M. W. (1999). Differences in coping effectiveness and well-being among aging mothers and fathers of adults with mental retardation. *American Journal on Mental Retardation, 104*, 545–563. https://doi.org/10.1352/0895-8017(1999)104<0545:DICEAW>2.0.CO;2

Ferguson, P. M. (2000). Mapping the family: Disability studies and the exploration of parental response to disability. In G.L. Albrecht, K.D. Seelman & M. Bury (Eds.), *Handbook of disability studies* (pp. 373-395). Sage. https://doi.org/10.4135/9781412976251.n15, PMid:11692516

Folkman S. (1984) Personal control and stress and coping processes: a theoretical analysis. *Journal of Personality and Social Psychology, 46*, 839–852. https://doi.org/10.1037/0022-3514.46.4.839

Gardner, J., & Harmon, T. (2002). Exploring resilience from a parent's perspective: A qualitative study of six resilient mothers of children with an intellectual disability. *Australian Social Work*, *55*(1), 60–68. https://doi.org/10.1080/03124070208411672

Gerstein, E. D., Crnic, K. A., Blacher, J., & Baker, B. L. (2009). Resilience and the course of daily parenting stress in families of young children with intellectual disabilities. *Journal of Intellectual Disability Research*, *53*(12), 981–997.https://doi.org/10.1111/j.1365-2788.2009.01220.x, PMid:19874449 PMCid:PMC2796238

Gohel, M., Mukherjee, S., & Choudhary, S. (2011). Psychosocial impact on the parents of mentally retarded children in Anand district. *Healthline*, *2*(1), 62–66.

Goodley, D & McLaughlin, J. (2008). Productive parental alliances. In J. McLaughlin, D. Goodley, E. Clavering, et al. (Eds.), *Families raising disabled children Enabling care and social justice* (pp. 78-104). Palgrave Macmillan. https://doi.org/10.1057/9780230583511_5

Grant, G., Ramcharan, P., & Flynn, M. (2007). Resilience in families with children and adult members with intellectual disabilities: Tracing elements of a psycho-social model. *Journal* *of Applied Research in Intellectual Disabilities, 20*(6), 563–575. https://doi.org/10.1111/j.1468-3148.2007.00407.x

Greeff, A. P., & Walt, K.-J. van der. (2010). Resilience in families with an autistic child. *Education and Training in Autism and Developmental Disabilities*, *45*(3), 347–355.

Green, S. E. (2007). "We're tired, not sad": Benefits and burdens of mothering a child with a disability. *Social Science and Medicine, 64* (1), 150-163. https://doi.org/10.1016/j.socscimed.2006.08.025, PMid:17014946

Hastings, R.P. & Taunt, H. M. (2002). Positive perceptions in families of children with developmental disabilities. *American Journal of Mental Retardation 107*, 116-127. https://doi.org/10.1352/0895-8017(2002)107<0116:PPIFOC>2.0.CO;2

Heiman, T. (2002). Parents of children with disabilities: resilience, coping and future expectations. *Journal of Developmental and Physical Disabilities, 14*(2), 159–171. https://doi.org/10.1023/A:1015219514621

John, A. (2012). Stress among mothers of children with intellectual disabilities in urban India: Role of gender and maternal coping. *Journal of Applied Research in Intellectual Disabilities*, *25*(4), 372–382. https://doi.org/10.1111/j.1468-3148.2011.00672.x, PMid:22711485

Judge, S. L. (1998). Parental coping strategies and strengths in families of young children with disabilities. *Family Relations*, *47*(3), 263–268. https://doi.org/10.2307/584976

Kandel, I., & Merrick, J. (2003). The birth of a child with disability: Coping by parents and siblings. *The Scientific World Journal, 3*, 741-750. https://doi.org/10.1100/tsw.2003.63 PMid:12953123 PMCid:PMC5974612

Kim, H. W., Greenberg, J. S., Seltzer, M. M., & Krauss, M. W. (2003). The role of coping in maintaining the psychological well-being of mothers of adults with intellectual disability and mental illness. *Journal of Intellectual Disability Research*, *47*(4/5), 313–327. https://doi.org/10.1046/j.1365-2788.2003.00493.x, PMid:12787163

Kishore, M. T. (2011). Disability impact and coping in mothers of children with intellectual disabilities and multiple disabilities. *Journal of Intellectual Disabilities*, *15*(4), 241–251. https://doi.org/10.1177/1744629511431659, PMid:22158461

Kishore, M. T., Behera, P., & Verma, R. K. (2004). Perceived burden and coping strategies in mothers of children with multiple disabilities. In *Proceedings of NIMH Conference on Multiple Disabilities* (pp. 123–131). National Institute for the Mentally Handicapped, India.

Knestrict, T., & Kuchey, D. (2009). Welcome to Holland: Characteristics of resilient families raising children with severe disabilities. *Journal of Family Studies*, *15*(3), 227–244. https://doi.org/10.5172/jfs.15.3.227

Knight, K. (2013). The changing face of the "good mother": trends in research into families with a child with intellectual disability, and some concerns. *Disability & Society*, *28*(5), 660–673. https://doi.org/10.1080/09687599.2012.732540

Kolar, K. (2011). Resilience: Revisiting the concept and its utility for social research. *International Journal of Mental Health and Addiction*, *9*(4), 421–433. https://doi.org/10.1007/s11469-011-9329-2

Koydemir-Özden, S., & Tosun, Ü. (2010). A qualitative Approach to understanding Turkish mothers of children with autism: Implications for counselling. *Australian Journal of Guidance & Counselling*, *20*(1), 55–68. https://doi.org/10.1375/ajgc.20.1.55

Landsman, G. (2003). Emplotting children's lives: developmental delay vs. disability. *Social Science & Medicine*, *56*(9), 1947–1960. https://doi.org/10.1016/S0277-9536(02)00215-0

Larson, E. (1998). Reframing the meaning of disability to families: the embrace of paradox. *Social Science Medicine, 47* (7) 865-875. https://doi.org/10.1016/S0277-9536(98)00113-0

Lazarus, R. (1993). Coping theory and research: past, present, and future. *Psychosomatic Medicine, 55*, 234–247. https://doi.org/10.1097/00006842-199305000-00002, PMid:8346332

Lazarus R (1999). *Stress and Emotion: A New Synthesis*. Springer.

Lazarus R, Folkman S (1984). *Stress, Appraisal, and Coping*. Springer.

Lee, J. H., Nam, S. K., Kim, A.-R., Kim, B., Lee, M. Y., & Lee, S. M. (2013). Resilience: A Meta-Analytic Approach. *Journal of Counseling & Development*, *91*(3), 269–279. https://doi.org/10.1002/j.1556-6676.2013.00095.x

Lee, T. Y., Cheung, C. K., & Kwong, W. M. (2012). Resilience as a Positive Youth Development Construct: A Conceptual Review. *The Scientific World Journal*, *2012*, 1–9. https://doi.org/10.1100/2012/390450, PMid:22623893 PMCid:PMC3353472

Lloyd, T. J., & Hastings, R. (2009). Hope as a psychological resilience factor in mothers and fathers of children with intellectual disabilities. *Journal of Intellectual Disability Research*, *53*(12), 957–968. https://doi.org/10.1111/j.1365-2788.2009.01206.x, PMid:19744261

Luthar, S. S. (1991). Vulnerability and resilience: a study of high-risk adolescents. *Child Development*, 62(3), 600–616.https://doi.org/10.1111/j.1467-8624.1991.tb01555.x, PMid:1914628 PMCid:PMC4235608

Luthar, S. S., & Cicchetti, D. (2000). The construct of resilience: Implications for interventions and social policies. *Development and Psychopathology*, *12*(4), 857–885. https://doi.org/10.1017/S0954579400004156, PMid:11202047 PMCid:PMC1903337

Luthar, S. S., Cicchetti, D., & Becker, B. (2000). The Construct of resilience : A critical evaluation and guidelines for future work. *Child Development 71*(3), 543–562. https://doi.org/10.1111/1467-8624.00164, PMid:10953923 PMCid:PMC1885202

Lyons, A. M., Leon, S. C., Roecker Phelps, C. E., & Dunleavy, A. M. (2010). The Impact of child symptom severity on stress among parents of children with ASD: The moderating role of coping styles. *Journal of Child and Family Studies*, *19*(4), 516–524. https://doi.org/10.1007/s10826-009-9323-5

McConkey, R., Truesdale-Kennedy, M., Chang, M.-Y., Jarrah, S., & Shukri, R. (2008). The impact on mothers of bringing up a child with intellectual disabilities: A cross-cultural study. *International Journal of Nursing Studies*, *45*(1), 65–74. https://doi.org/10.1016/j.ijnurstu.2006.08.007, PMid:17022985

McConnell, D., Savage, A., & Breitkreuz, R. (2014). Resilience in families raising children with disabilities and behavior problems. *Research in Developmental Disabilities*, *35*(4), 833–848.

https://doi.org/10.1016/j.ridd.2014.01.015, PMid:24491480

McConnell, D., Savage, A., Sobsey, D., & Uditsky, B. (2015). Benefit-finding or finding benefits? The positive impact of having a disabled child. *Disability & Society*, *30*(1), 29–45. https://doi.org/10.1080/09687599.2014.984803

Mirsaleh, Y. R., Rezai, H., Khabaz, M., Afkhami Ardekani, I., & Abdi, K. (2011). Personality dimensions, religious tendencies and coping strategies as predictors of general health in Iranian mothers of children with intellectual disability: A comparison with mothers of typically developing children. *Journal of Applied Research in Intellectual Disabilities*, *24*(6), 573–582. https://doi.org/10.1111/j.1468-3148.2011.00639.x

Murphy, N. A., Christian, B., Caplin, D. A., & Young, P. C. (2007). The health of caregivers for children with disabilities: caregiver perspectives. *Child: Care, Health and Development*, *33*(2), 180–187. https://doi.org/10.1111/j.1365-2214.2006.00644.x, PMid:17291322

Olsson, C. A., Bond, L., Burns, J. M., Vella-Brodrick, D. A., & Sawyer, S. M. (2003). Adolescent resilience: a concept analysis. *Journal of Adolescence*, *26*(1), 1–11. https://doi.org/10.1016/S0140-1971(02)00118-5

Olsson, M. B. (2008). Understanding individual differences in adaptation in parents of children with intellectual disabilities: A risk and resilience perspective. In L. M. Glidden (Ed.), *International Review of Research in Mental Retardation* (Vol. 36, pp. 281–315). Academic Press https://doi.org/10.1016/S0074-7750(08)00008-6

Patterson, J. M. (2002). Integrating family resilience and family stress theory. *Journal of Marriage and Family*, *64*(2), 349–360.https://doi.org/10.1111/j.1741-3737.2002.00349.x

Peer, J. W., & Hillman, S. B. (2014). Stress and Resilience for Parents of Children With Intellectual and Developmental Disabilities : A Review of Key Factors and Recommendations for Practitioners. *Journal of Policy and Practice in Intellectual Disabilities*, *11*(2), 92–98. https://doi.org/10.1111/jppi.12072

Peshawaria, R., Menon, D., Ganguly, R., Roy, S., Pillay, R. P. R. S., & Gupta, A. (1995). U*nderstanding Indian families having persons with mental retardation*. National Institute for the Mentally Handicapped, India.

Pilusa, N. E. (2006). *The impact of mental retardation on family functioning* [Master's thesis, University of Pretoria]. UPSpace Institutional Repository. https://repository.up.ac.za/handle/2263/28013

Pottie, C. G., & Ingram, K. M. (2008). Daily stress, coping, and well-being in parents of children with autism: A multilevel modeling approach. *Journal of Family Psychology*, *22*(6), 855–864. https://doi.org/10.1037/a0013604, PMid:19102606

Reichman, N. E., Corman, H., & Noonan, K. (2008). Impact of Child Disability on the Family. *Maternal and Child Health Journal*, *12*(6), 679–683. https://doi.org/10.1007/s10995-007-0307-z, PMid:18060488

Rutter, M. (2006). Implications of resilience concepts for scientific understanding. *Annals of the New York Academy of Sciences*, *1094*, 1–12. https://doi.org/10.1196/annals.1376.002, PMid:17347337

Rutter, M. (2007). Resilience, competence, and coping. *Child Abuse & Neglect*, *31*(3), 205–209. https://doi.org/10.1016/j.chiabu.2007.02.001, PMid:17408738

Rutter, M. (2013). Annual research review: Resilience - clinical implications. *Journal of Child Psychology and Psychiatry*, *54*(4), 474–487. https://doi.org/10.1111/j.1469-7610.2012.02615.x, PMid:23017036

Ryan, S., & Runswick-Cole, K. (2008). Repositioning mothers: mothers, disabled children and disability studies. *Disability & Society*, *23*(3), 199–210. https://doi.org/10.1080/09687590801953937

Scorgie, K., & Sobsey, D. (2000) Transformational outcomes associated with parenting children who have disabilities. *Mental Retardation 38*, 195–206. https://doi.org/10.1352/0047-6765(2000)038<0195:TOAWPC>2.0.CO;2

Seltzer M. M., Greenberg J., & Krauss M. (1995). A comparison of coping strategies of aging mothers of adults with mental illness or mental retardation. *Psychology and Aging* 10, 64–75. https://doi.org/10.1037/0882-7974.10.1.64

Seltzer, M. M., Floyd, F., Song, J., Greenberg, J., & Hong, J. (2011). Midlife and aging parents of adults with intellectual and developmental disabilities: impacts of lifelong parenting. *American Journal on Intellectual and Developmental Disabilities*, *116*(6), 479–499. https://doi.org/10.1352/1944-7558-116.6.479, PMid:22126660 PMCid:PMC3263696

van der Veek, S. M. C., Kraaij, V., & Garnefski, N. (2009). Down or up? Explaining positive and negative emotions in parents of children with Down's syndrome: Goals, cognitive coping, and resources. *Journal of Intellectual and Developmental Disability*, *34*(3), 216–229. https://doi.org/10.1080/13668250903093133, PMid:19681002

Walsh, F. (2003). Family Resilience: A Framework for Clinical Practice. *Family Process*, *42*(1), 1–18. https://doi.org/10.1111/j.1545-5300.2003.00001.x, PMid:12698595

Walsh, F. (2008). Understanding theory to support a family resilience framework in practice. *Social Work Now*, *39*, 5–14.

Winders, S. (2014). From extraordinary invulnerability to ordinary magic: A literature review of resilience. *Journal of European Psychology Students, 5*(1), 3–9. https://doi.org/10.5334/jeps.bk

Wu, G., Feder, A., Cohen, H., Kim, J. J., Calderon, S., Charney, D. S., & Mathé, A. A. (2013). Understanding resilience. *Frontiers in Behavioral Neuroscience*, *7*(February), 1–15. https://doi.org/10.3389/fnbeh.2013.00010, PMid:23422934 PMCid:PMC3573269

Ylvén, R., Björck-Åkesson, E., & Granlund, M. (2006). Literature review of positive functioning in families with children with a disability. *Journal of Policy and Practice in Intellectual Disabilities*, *3*(4), 253–270. https://doi.org/10.1111/j.1741-1130.2006.00089.x

Zablotsky, B., Bradshaw, C. P., & Stuart, E. A. (2013). The association between mental health, stress, and coping supports in mothers of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, *43*(6), 1380–1393. https://doi.org/10.1007/s10803-012-1693-7, PMid:23100053

REVIEWS

Access to Public Healthcare Rehabilitation Services by Persons with Disabilities in South Africa: a Scoping Review

Hester M van Biljon[1]*, Bianca Salie[1], Jancke C van Wyk[1], Jessica Daniel[1], Lize-Mari Kersop[1], Michaela Naidoo[1], Lana van Niekerk[1]

1. Stellenbosch University, Faculty of Medicine and Health Sciences, Department of Health and Rehabilitation Sciences, Division Occupational Therapy, Tygerberg, South Africa

ABSTRACT

Purpose: *The South African National Health System, funded by National Health Insurance, aims to ensure universal access to quality healthcare for all South Africans. The aim of this scoping review was to explore barriers and facilitators experienced by persons with disabilities when accessing rehabilitation services in public healthcare facilities in South Africa. For this scoping review, disability was seen as defined in the International Classification of Functioning, Disability and Health (ICF), and access was understood to include availability, accessibility, acceptability, and affordability of rehabilitation.*

Method: *Sources were included if they were published between 2012 and 2021, in English, and contained primary research undertaken in South Africa pertaining to accessibility to public healthcare facilities for rehabilitation by persons with disabilities. Following Joanna Briggs Institute guidelines, the search included CINAHL, EBSCOhost, Scopus, Web of Science, PubMed, Science Direct, SciELO, and Google Scholar. Rayyan was used to screen sources for eligibility. Ineligible sources were removed, based on titles and abstracts, and the eligibility of remaining sources was confirmed in the full texts review. Although 70 sources were identified and screened, only 19 were found to be eligible for inclusion. Data was extracted on Microsoft Excel and Word templates. Analysis and synthesis were done using Microsoft Excel and Taguette.*

Results: *The findings showed that the most prominent barrier restricting the access of persons with disability to rehabilitation was affordability. Other barriers were availability and acceptability of services. Physical access to rehabilitation*

---

* **Corresponding Author:** Hester M van Biljon, Post-Doctoral Fellow, P O Box 830, Auckland Park, 2006, South Africa. Email: HesterMvanBiljon@gmail.com

was affected by inaccessible transport and community mobility, social and community barriers. The facilitators that were most prevalent were personal attitudes, family and friends - societal and community - and governmental support.

Conclusion and Implications: *This scoping review confirmed that access to rehabilitation services in public healthcare facilities in South Africa is a multifaceted issue, which requires a multisectoral approach to achieve sustainable and effective solutions. Intersectoral and interprofessional approaches by public healthcare rehabilitation service providers and stakeholders are necessary to improve access to services.*

Better reliance on facilitators that are already in place should improve access to rehabilitation services. This includes improved collaboration with community leaders, family members and users of disability services.

Key words: *affordability, acceptability, availability, interprofessional rehabilitation services, public healthcare, barriers, facilitators to rehabilitation*

INTRODUCTION

According to the World Health Organisation (WHO), achievement of the highest attainable standard of health is a fundamental right of every human being (Meier, 2017). In its report on disability (WHO, 2011)the WHO clearly indicates that this includes persons with disabilities. Disability is understood to be *an umbrella term for impairments, activity limitations, and participation restrictions, (*denoting*) the negative aspects of the interaction between an individual* (International Classification of Functioning, Disability and Health (ICF), 2001). Towards realisation of this right to health, the availability, accessibility, acceptability and affordability of healthcare require consideration(Evans , Hsu, Boerma., 2013) . In South Africa such access to healthcare is enshrined in the Constitution (The Constitution of the Republic of South Africa, 1996) and envisioned by the National Health System (National Department of Health, 2017) which endeavours to ensure universal access to quality healthcare for all South African citizens and residents irrespective of their personal and socio-economic status. There are, however, challenges in the materialisation of these ideals. Availability of health workers, with the competencies and skill-mix to match the health needs of the population, is especially problematic in South African public healthcare facilities, despite governmental strategies to counter this (Maphumulo & Bhengu, 2019). Access to healthcare is affected by inequitable distribution of health facilities, inaccessible transport and infrastructure (van Biljon & van Niekerk, 2021). The acceptability of services, evidenced by the extent to which people are willing to use available healthcare services, is influenced by the biographics of providers and users of health services (Ned, Cloet &, Mji., 2017), social, and cultural barriers (Neille & Penn, 2015). The affordability of available healthcare has been shown to be a main driver of healthcare inequality in South Africa (Gordon, Booysen & Mbonigaba., 2020)). Even with high levels of acceptability of health services, the availability and affordability remained low, especially for vulnerable subgroups (Burger & Christian., 2020). Persons with disability using rehabilitation services within public healthcare are one such vulnerable group.

A literature review (Chiluba, 2019) confirmed that persons with disability from low-income countries faced more barriers to healthcare than the average population; these findings were supported by a national cross-sectional multistage cluster sample survey (N=1738) done in Afghanistan (Trani, Bakhshi, Noor, Lopez & Mashkoor., 2010)) and a survey (N=773) exploring access to healthcare for persons with disability in rural South Africa (Vergunst, Swart, Hem, Eide, Mannan, MacLachlan, Mji, & Braathen., 2017) . Despite aspirations that health should be universally accessible and despite the country's progressive policies, this is not the case for many sections of South African society. The National Health Act was promulgated in 2003 (National Health Act 61 of 2003, 2003) and in 2012 the implementation phase of the National Health Insurance (NHI) commenced, with the focus on Health System Strengthening (HSS) initiatives. In 2019, the NHI was tabled in Parliament for the final opportunity for amendment and contribution. Myezwa & van Niekerk (2013) considered the implications of these HSS initiatives for rehabilitation professionals, their service delivery and the impact on rehabilitation service users. They urged that rehabilitation professionals be proactive and research aspects that impact on the equitability of their service delivery.

Examining the access of service users to rehabilitation services offered by rehabilitation professionals is one such effort. The authors of this article attempted to explore how rehabilitation service users get to service providers that offer rehabilitation services in public healthcare facilities. For this scoping review, rehabilitation services were seen as those offered by rehabilitation service providers within the professions of occupational therapy, medical orthotics and prosthetics, arts therapy including drama, music, art and movement, physiotherapy, podiatry and biokinetics, speech and hearing and audiology, and optometry. A specific focus was on rehabilitation services offered to outpatients and/or community-dwelling service users.

Objective

The aim of the scoping review was to explore barriers and facilitators to accessing rehabilitation services within public healthcare in South Africa. *Access* was understood to comprise availability, accessibility, acceptability, and affordability. The review sought to answer the question: What are the barriers and facilitators persons with disabilities experience as rehabilitation service users in South Africa's public healthcare?

METHOD

Study Design

The review was undertaken between 29th March 2021 and 1st April 2021. The authors comprised five Stellenbosch University final year occupational therapy students and two supervisors. The review was conducted according to the Joanna Briggs Institute (JBI) methodological framework for scoping reviews (Peters, M.D.J., Godfrey, C., McInerney, P., Baldini Soares, C., Khalil, H. and Parker, 2017) . Mendeley Reference Manager (2020) , a no-cost web and desktop reference management application, was used to import, de-duplicate, organise, and export articles. Rayyan (Rayyan Sytems, 2020), a no-cost web application designed for reviews and knowledge synthesis projects, was used to screen articles. Microsoft Excel and Taguette (Rampin, Rampin & DeMott., 2020), a no-cost and open-source qualitative research tool, were used to analyse and synthesise findings.

Search Strategy, Screening, and Selection

The search string comprised "persons with disabilities" or "PWD" or "people with disabilities", "access rehabilitation services", "public health care", "poverty and healthcare" and "South Africa"; with date limiters set to identify sources from January 2012 (the year in which the NHS policy was adopted) to March 2021. The following databases were searched through Stellenbosch University Library:

CINAHL, EBSCOhost, Scopus, Web of Science, PubMed, Science Direct, SciELO, and Google Scholar.

Eligibility criteria:

Reported primary research, undertaken in South Africa, and published in English peer-reviewed journals, between 2012 and 2021.

Using the PCC (Population/Concept/Context) mnemonic the following criteria were formulated:

- Population - Persons with disability who are public healthcare rehabilitation services users in South Africa, inclusive of all types of disabilities, gender, race, and age groups.
- Concept - Access to rehabilitation services as offered in occupational therapy, medical orthotics and prosthetics; arts therapy including drama, music, art and movement; physiotherapy, podiatry and biokinetics, speech and hearing and audiology, and optometry. All barriers faced when accessing public healthcare include transport and community mobility, physical accessibility issues, financial, educational, geographic, personal, and social perceptions. All facilitators employed to overcome these.
- Context - Access to rehabilitation services offered at a public healthcare facility in South Africa, primary healthcare clinics, community health clinics, secondary, tertiary or quaternary hospitals and rehabilitation hospitals in rural and urban areas.

The identified articles were uploaded into Mendeley, duplicates were removed, and the availability of full texts confirmed. Full texts were loaded into Rayyan. Six authors screened the sources. First, the titles and abstracts of all sources were screened by blinded reviewers to identify the ones that were provisionally eligible; next, blinded full text screening ensued to confirm eligibility. Conflicts that arose were resolved by means of regular group discussions. The results of the searches and selection process are reported in Figure 1 as a PRIMSA-ScR flow chart (Tricco, Lillie, Zarin, O'Brien, Colquhoun Levac, Moher, Peters, Horsley, Weeks, Hemple, Akl, Chang, McGowan, Stewart, Harling, Aldcroft, Wilson, Garritty, Lewin, Godfrey, MacDonald, Langlois, Soares-Weiser, Moriarty, Clifford, Tuncalp & Straus, 2018) .

Data Extraction, Analysis, and Synthesis

Data was extracted and charted using data extraction templates.

Quantitative data was extracted into an Excel sheet template with the following data fields: Author/s, Short title, Journal name, Year of publication, Study design, Data collection process/tools, Ethical affiliation, Number of people with disabilities participants, Number of other participants, Age range of people with disabilities participants, Gender (male/female/other), Socio-economic status, Education level, Type of disability, Race/Culture/Language, Province, Geographic region, Rehabilitation service used, Healthcare facility visited, Mobility mode used to access rehabilitation.

Qualitative data was extracted in Taguette and is shown in Table 1.

Table 1: Qualitative Data Extraction Template

Barriers	**Strategies**
Multiple factorial barriers The interplay of multiple factors that escalate to become a barrier to get to rehabilitation	Positive effect, experience, or evidence of rehabilitation services
Physical environmental barriers Geographical, geological, environmental aspects that affect ability to get to rehabilitation	Societal and community support and strategies allowing ability to attend rehabilitation
Crime barriers	Financial strategies
Transport barriers The unavailability of transport, poor quality of transport, unreliability of transport	Personal and attitudinal strategies
Rehabilitation service barriers No or poor-quality rehabilitation services, unavailability of rehabilitation services, communication and language barriers	Insight and educational strategies
Disability-related barriers When a disability or lack of ability to manage it affects access to rehabilitation	Transport strategy
Societal community barriers Social attitudes or community conditions affect ability to get to rehabilitation	Rehabilitation services strategies

Personal and attitudinal barriers Insight/educational/knowledge barriers Attitudinal barriers are pervasive negative perceptions and value systems that focus on a person's disability rather than their ability and other valued characteristics. Attitudinal barriers may be present in societies, communities or in specific individuals.	Physical environmental strategies
Financial barriers	Disability-related strategy
Political barriers	Political strategies

Both data extraction templates were developed for the review through an iterative group discussion process and refined during a process of collective screening of the first three sources; thereafter five authors extracted all data and met on a weekly basis to discuss progress and resolve problems. The quality of the published research was not critically appraised. As the review question could be answered by both qualitative and quantitative data, a convergent integrated approach to the analysis and synthesis was used. Focusing on the review question and objectives, the extracted and analysed data was inductively coded through group discussion on relevance and value of the evidence for rehabilitation practice in South Africa. The most salient codes were identified and narratively summarised under the two pre-determined themes of barriers and facilitators.

Ethics Approval

No ethical clearance was required for the scoping review.

RESULTS

Study Selection

Of the 70 articles yielded in the search, 19 were identified to be relevant. Figure 1 shows a PRISMA Scoping Review flow chart detailing the search and screening processes.

Figure 1: PRISMA Scoping Review Flow Chart

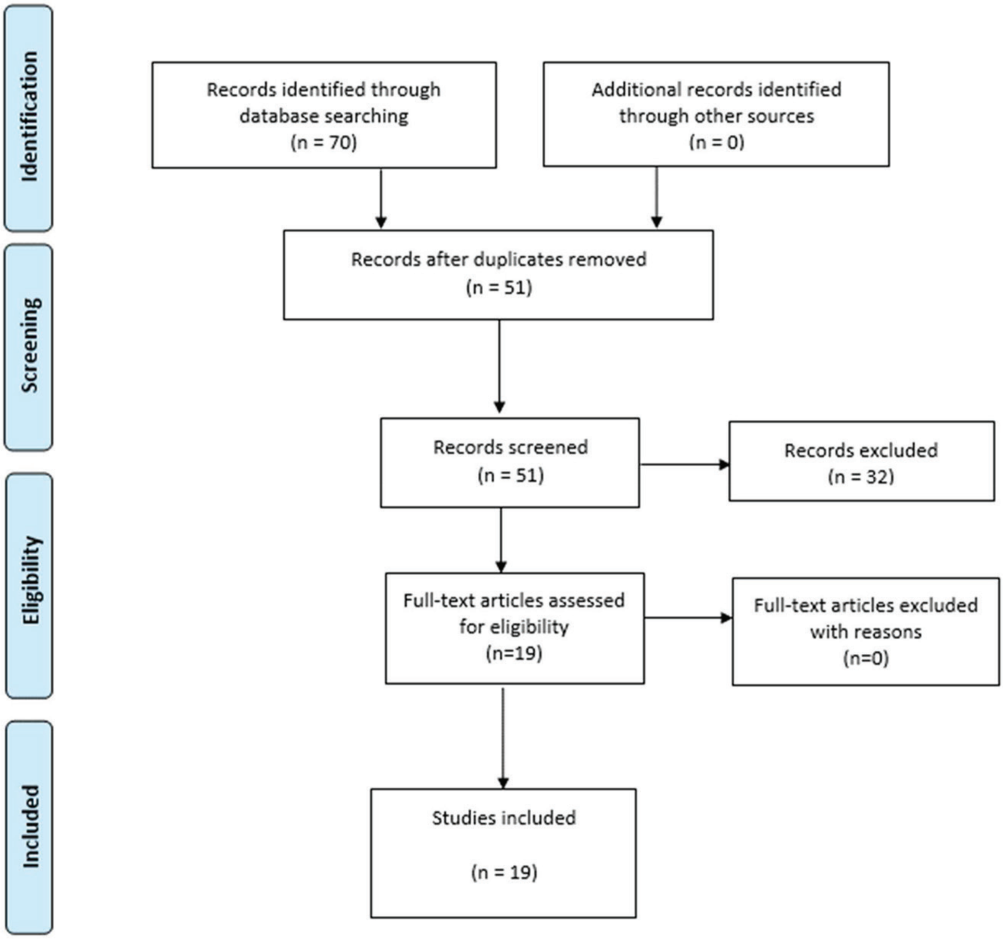

Table 2 shows the 19 articles included in the review, presented in alphabetical order based on the name of the first author. The authors are from different professions and affiliations, mostly in healthcare, and the articles were published in a variety of journals, most of them based in Africa.

Table 2: Articles included in the Scoping Review

No.	Article Referenced
1	Cobbing S, Hanass-Hancock J, Deane M. Physiotherapy rehabilitation in the context of HIV and disability in KwaZulu-Natal, South Africa. *Disability and Rehabilitation* 2014; 36: 1687–1694.

2	de Klerk S, Eloff L, Naudé Z, Boon A, Carelse M, Steward M, Minal Z. Non-attendance of occupational and physiotherapy appointments at Western Cape Rehabilitation Centre: A description of associated factors. *South African Journal of Occupational Therapy* 2019; 49: 54–63.
3	Grut L, Mji G, Braathen SH, Ingstad B. Accessing community health services: challenges faced by poor people with disabilities in a rural community in South Africa. *African Journal of Disability* 2012; 1: 1–7.
4	Hussey M, MacLachlan M, Mji G. Barriers to the implementation of the health and rehabilitation articles of the United Nations convention on the rights of persons with disabilities in South Africa. *International Journal of Health Policy Management* 2017; 6: 207–218.
5	Joosub N. How local context influences access to neuropsychological rehabilitation after acquired brain injury in South Africa. *BMJ Global Health* 2019; 4: 1–4.
6	Kritzinger J, Schneider M, Swartz L, Braathen SH. 'I just answer "yes" to everything they say': Access to health care for deaf people in Worcester, South Africa, and the politics of exclusion. *Patient Education and Counselling* 2014; 94: 379–383.
7	Kumurenzi A, Goliath C, Mji G, Mlenzana N, Joseph C, Stathum S, Rhoda A. Experiences of patients and service providers with out-patient rehabilitation services in a rehabilitation centre in the Western Cape Province. *African Journal of Disability* 2015; 4: 1–7.
8	Maddocks S, Moodley K, Hanass-Hancock J, Cobbing S, Chetty V. Children living with HIV-related disabilities in a resource-poor community in South Africa: caregiver perceptions of caring and rehabilitation. *AIDS Care - Psychology Socio-Medical Asp AIDS/HIV* 2020; 32: 471–479.
9	Mlenzana N, Eide A, Frantz J. The Profile and Experiences of Service Providers with Rehabilitation Services in the Western Cape. *South African Journal of Physiotherapy* 2014; 70: 19–24.
10	Moodley J, Ross E. Inequities in health outcomes and access to health care in South Africa: a comparison between persons with and without disabilities. *Disability and Society* 2015; 30: 630–644.

11	Morris LD, Grimmer KA, Twizeyemariya A, et al. Health system challenges affecting rehabilitation services in South Africa. *Disability and Rehabilitation* 2021; 43: 877–883.
12	Mutwali R, Ross E. Disparities in physical access and healthcare utilisation among adults with and without disabilities in South Africa. *Disability and Health Journal* 2019; 12: 35–42.
13	Naidoo U, Ennion L. Barriers and facilitators to utilisation of rehabilitation services amongst persons with lower-limb amputations in a rural community in South Africa. *Prosthetics and Orthotics International* 2019; 43: 95–103.
14	Ntamo NP, Buso D, Longo-Mbenza B. Factors affecting poor attendance for outpatient physiotherapy by patients discharged from Mthatha general hospital with a stroke. *South African Journal of Physiotherapy* 2013; 69: 13–18.
15	Scheffler E, Visagie S, Schneider M. The impact of health service variables on healthcare access in a low resourced urban setting in the Western Cape, South Africa. *African Journal of Primary Health Care and Family Medicine* 2015; 7: 1–11.
16	Schierenbeck I, Johansson P, Andersson L, van Rooyen D. Barriers to accessing and receiving mental healthcare in Eastern Cape, South Africa. *Health and Human Rights* 2013; 15: 110–123.
17	Vergunst R, Swartz L, Mji G, MacLachlan M, Mannan H. ‘You must carry your wheelchair’ - barriers to accessing healthcare in a South African rural area. *Global Health Action* 2015; 8: 1–8.
18	Visagie S, Swartz L. Rural South Africans’ rehabilitation experiences: Case studies from the Northern Cape Province. *South African Journal of Physiotherapy* 2016; 72: 1–8.
19	Wegner L, Rhoda A. The influence of cultural beliefs on the utilisation of rehabilitation services in a rural South African context: Therapists’ perspective. *African Journal of Disability*. 2015; 4: 1

Study Extracted Criteria

Table 3 provides a summary of the data that was extracted to elucidate the barriers and facilitators that impacted access to rehabilitation, and the recommendations and conclusions made in articles that were included in the review.

Table 3: Extracted Barriers, Facilitators, and Conclusions that affect Persons with Disabilities

Article No. and 1st Author	Barriers to access Rehabilitation	Facilitators to access Rehabilitation	Recommendations made by Authors
1. Cobbing et al	• Societal community stigma • Lack of knowledge of condition and intervention • Disability and structural related restrictions • Financial and transport • Multiple factorial barriers	• Positive rehabilitation experience • Personal attitudes / mental strength	Develop and implement home-based rehabilitation interventions. Rehabilitation professionals should keep up to date with recent literature and practical training courses.
2. de Klerk et al	• Time of the year / month / week and weather • Dependant responsibilities. The more dependants the lower the attendance rate • Low socio-economic category • Type of diagnoses and impairment	• Being married	Further studies are needed to assist in implementing solutions to reduce high rates of non-attendance.
3. Grut et al	• Lived poverty and resource-poor area • Poor perspective of the health services • Lack of availability of rehabilitation service • Lack of knowledge of rehabilitation • Out of reach healthcare services • Poor infrastructure and transport • Complexity and multiple factorial interaction of social, cultural, and political barriers	• Decentralised healthcare facilities • Multi-professional rehabilitation services	Access should transcend a medical institution focus. Health service models that integrate the skills of health professionals with those of people with disability and their family. Such skills lie dormant at community level and need to be recognised and utilised.

4. Hussey et al	• Government officials' lack of knowledge, stigma, and negative assumptions about people with disabilities • Lack of coordination between government departments • Poor funding of rehabilitation services • Persons with disabilities' financial constraints • Overburdened health system • Inaccessible / non-existent transportation and infrastructure • Communicating with rehabilitation professionals • Multiple factorial barriers	• Financial assistance from the governmental grant system • Social and family assistance	Greater sensitisation around disability is needed. People with disabilities' needs should be better integrated and mainstreamed into healthcare services.
5. Joosub	• Socio-economic disparities: Material exploitation and class inequality are an enduring legacy of fragmented healthcare systems and skewed geopolitical priorities	• The concept of Ubuntu, which emphasises inter-connectedness, interdependence, and the importance of communal relationships	Inclusive models of healthcare. Resource constraints necessitate creative and ecological forms of rehabilitation interventions.
	• Sociocultural influences: African traditional beliefs were excluded from the healthcare system. Indigenous healing and beliefs have been overshadowed by mainstream medical models • Discharge to underprepared communities: Family members and communities are underprepared and have a lack of adequate support and knowledge to deal with individual's need for care		Collaborate with existing leaders like traditional healers and religious clerics. Consider contextual influences to improve accessibility and relevance of rehabilitation and ensure effective utilisation of scarce healthcare resources.

6. Kritzinger et al	• Communication difficulties at healthcare facilities • Persons with disabilities' lack of independent thought, overprotectedness and non-questioning attitude • Lack of familial communication	None	Broader provision of interpreting services. Assist deaf users to engage assertively with the health system.
7.Kumurenzi et al	• Service providers lacked knowledge and skills in dealing with some disabilities • Transport to get to rehabilitation • Waiting time for rehabilitation session, the length of sessions and appointment schedules • Poor communication and provision of information at healthcare facilities	• Positive rehabilitation experiences • Society and community support	Increase the capacity of service providers and provide transport services for persons with disabilities.
8. Maddocks et al	• Financial constraints • Poor access to rehabilitation • Lack of support networks	• Societal, family, and spiritual support • Insight and knowledge • Political facilitators • Financial grants	Changes in government policy guiding rehabilitation interventions are needed to improve the availability of resources.
9. Mlenzana et al	• Accessibility within the centre • Language barriers • Shortage of rehabilitation professionals • Resources and budget challenges • Relevance of service provider skills • Transport challenges for persons with disabilities	• Family involvement and support • Societal and community support	Reorganise rehabilitation services to improve accessibility to these services while maintaining service quality.

10. Moodley et al	• Lack of knowledge of rehabilitation • Unavailability of services and inaccessibility of health facilities • Financial constraints • Ignorance regarding available services • Inadequate and inaccessible transport	None	Disability-friendly health care policies that address barriers. The planned National Health Insurance scheme is likely to benefit persons with disabilities.
11. Morris et al	• Poverty • Inaccessible transport and infrastructure • Inter relational impact of factors • Crime and community unrest	• Support from community • Knowledge of / insight into and education regarding rehabilitation	Provision of equitable, accessible, affordable, and evidence-based rehabilitation. Measuring social, economic, and educational return on investment from rehabilitation.
12.Mutwali et al	• Variety of rehabilitation services are not always available • Poor physical access to and lack of transport and infrastructure • Lack of funds to get to rehabilitation • Long queues and waiting times for rehabilitation	• Health facilities were within walking distance	Reduce poverty. Barriers, disparities, and inequities in current healthcare can be reduced through the roll-out of National Health Insurance.
13. Naidoo et al	• Challenges utilising transport to the hospital • No referral or no knowledge of physiotherapy services at the nearest hospital • Poor bodily function was identified as a barrier • Personal insight, knowledge, and attitudinal barriers • Societal community barriers • Communication and language barriers	• Self- motivation to improve • Positive experiences • Shorter waiting period • Family support	Therapists should foster good relationships with clients, educate, motivate, and encourage them. Early involvement and education of caregivers. A community-based approach to rehabilitation.

14. Ntamo et al	• Lack of finances / funds • Living a long distance from rehabilitation service • Insensitive public transport system especially taxi drivers who refused to transport wheelchairs • Rude attitudes from hospital staff	• Money • Multiple reasons to attend / go to a healthcare centre	Decentralisation of rehabilitation services to address unavailability at clinics and health care centres proximal to the clients' residential areas.
15. Scheffler et al	• Transport barriers • Societal community: attending a clinic robbed the users of confidentiality as their health status was publicly displayed • Rehabilitation services: language barriers, long waiting times, users' inability to plan / choose appointments and facilities to attend, short contact sessions, fragmentation of services, negative attitudes / behaviour of rehabilitation providers, lack of equipment and consumables and too few service providers, providers' lack of disability-specific knowledge • Financial barrier • Physical environmental barriers • Multiple factorial barriers	• Rehabilitation service within a 3 km radius of users and mostly accessible by foot • Rehabilitation providers were caring, positive, committed, and professional • Users felt they were treated in an acceptable manner	Focus on how services are delivered to restore supply (services) and demand (user needs) balance and promote universal equitable rehabilitation access. Service delivery should include a client-centred approach with consideration of aspects such as choice, comprehensive individualised care, continuity of care, shared consultation and participative decision making, non-discrimination, as well as good communication with a focus on mutual respect and courtesy.

16. Schierenbeck et al	• Lack of staff and properly trained staff • Lack of facilities • Lack of community services and prevention • Lack of affordable transport • Disability related barriers • Community, family and persons with disabilities' insight, education, and knowledge barriers • Traditional cultural beliefs of the community, persons with disabilities and staff • Lack of cross-cultural understanding, communication and language barriers	• Insight and educational facilitators • Persons with disabilities' personal and attitudinal facilitators	Monitor the implementation of the right to health and the experience and knowledge of service providers.
17. Vergunst et al	• Language and cultural difference between providers and users • Geographical barriers: transport, terrain, and distance • Healthcare institution and organisational barriers: inaccessible buildings, shortage of staff, long waiting period, difficult to get resources, shortage of stock and supplies • Attitudinal barriers within healthcare towards persons with disabilities, specifically negative attitudes toward individuals with psychosocial disabilities	• Societal and community support • Mobile health unit visits villages in the community: services reached the community rather than the community making the journey to the hospital	Stronger societal orientation towards social justice, poverty relief, and employment may improve attitudes to persons with disabilities. Seeing access to healthcare for rural South African persons with disabilities as a broader human rights issue.

18. Visagie et al	• Service barriers: Challenges with referral and communication, limited therapy hours in the community, the lack of community-based rehabilitation and the challenges regarding provision of assistive devices • Environmental barriers • Caregivers and services users' illiteracy and lack of knowledge of disability and rehabilitation	• Commitment shown by the primary caregivers served as a facilitator	Community-based rehabilitation and transdisciplinary teamwork supported by family members, community health workers and peer mentors.
19. Wegner et al	• Resistant to being treated by therapists from their own culture and race • Lack of conviction about the efficacy of rehabilitation • Staff shortages, lack of vehicles to do home and clinic visits • Accessibility to and availability of public transport • Public cultural beliefs regarding cause of disease, and that a person with disability was 'bewitched'	None	Educate and prepare rehabilitation providers to be culturally aware, knowledgeable of, and competent to meet the needs of rehabilitation service users in rural contexts.

DISCUSSION

The review findings confirmed that access to rehabilitation for persons with disabilities in South Africa is complex (van Stormbroek & Buchanan, 2019) with multiple factors impacting it (Hussey, MacLachlan, & Mji., 2017); (Bright, Wallace & Kuper,, 2018)) which further complicates strategies and attempts to address the associated problems (Vergunst, Swartz &Mji, 2015) . The same applies to factors that support and facilitate persons with disabilities' access to rehabilitation (Scheffler, Visagie & Schneider, 2015). Concluding recommendations of the 19 included articles appealed for social justice (Vergunst, Swart & Mji., 2015) and two of the articles called for the implementation of South Africa's planned national health initiatives (Moodley & Ross, 2015) (Mutwali & Ross, 2019) as a solution for the current healthcare inequity. Authors reported a shortage of research evidence and poor uniformity in reporting issues pertaining to accessibility to rehabilitation. Recommendations for further research to address issues relating to, and that could impact, accessibility to rehabilitation were made (De Klerk, Eloff, Naude, Boon, Carelse, Steward & Zaidi., 2019) .

Barriers, facilitators, and the concluding recommendations were used as categories to summarise the results of the review. All four of the accessibility-to-healthcare components, namely availability, accessibility, affordability and acceptability, were reported on and emerged as barriers. Facilitators that enabled access to rehabilitation for persons with disabilities, and that originated organically from within low-resourced communities, warrant consideration as potentially sustainable, low-cost, and acceptable solutions that might address accessibility. Grut, Mji, Braathen and Ingstad(, 2012) reported such solutions as *skills that lie dormant at community level*, and urged readers to be cognisant of these. Considering these as evidence to inform rehabilitation accessibility problems would require interprofessional, intersectoral collaboration and further research.

Barriers to Access Rehabilitation

Affordability was the most reported barrier preventing access to rehabilitation; this finding also pertained to access to public healthcare (van Gaans & Dent, 2018) globally (Akter, Davies, Rich & Inder., 2019) In this review, persons with disability who accessed rehabilitation services within public healthcare had to do so within a broader context of poverty (Vergunst et al., 2015)), which affected not only themselves but also the communities they lived in. The cost of getting to rehabilitation services (Schierenbeck, Johansson, Andersson & van Rooyen., 2013) (Scheffler et al., 2015) was identified as a barrier in all the reviewed articles. The high cost of transport, relative to income, mostly pertained to minibus taxis; the lack of affordable public or private transport alternatives was consistently reported (Mlenzana, Eide & Frantz, 2014) . Persons with disabilities were forced to pay extra for mobility assistive devices such as wheelchairs (Grut et al., 2012) . In addition, long waiting hours for rehabilitation services (Mutwali & Ross, 2019) (on average half a day) (Grut et al., 2012) , often resulted in loss of income and the threat of potential loss of work. The long waiting times might have been exacerbated by policies that dictate designated facilities, where appointments are made with little or no consideration to personal circumstance and without a specific time in the day (Kumurenzi, Goliath, Mji, Mlenzana, Joseph, Stathum & Rhoda., 2015) (Scheffler et al., 2015).

The availability of rehabilitation services was especially problematic in rural contexts (Grut et al., 2012), (Vergunst et al., 2015), (Visagie & Swartz, 2016), (Naidoo & Ennion, 2019). However, even in better resourced urban settings certain rehabilitation services were not available (Kumurenzi et al., 2015) . The reported barriers were staff shortages (Mlenzana et al., 2014) unavailability of rehabilitation (Moodley & Ross, 2015) and a limited range of rehabilitation services (Grut et al., 2012) . The latter was due to various reasons: poor funding of rehabilitation (Hussey et al., 2017) , lack of rehabilitation equipment and consumables (Vergunst et al., 2015) , no vehicles for home or clinic visits (Wegner & Rhoda, 2015) and overburdened services (Hussey et al., 2017). Limitations in rehabilitation providers' knowledge and experience (Cobbing et al., 2014) were reported in one source.

The physical inaccessibility of public transport (Mlenzana et al., 2014a) (Moodley & Ross, 2015) (Hussey et al., 2017)), infrastructure (Morris et al., 2021), the outdoor environment (Mutwali & Ross, 2019) and even healthcare facilities (Grut et al., 2012), (Moodley & Ross, 2015), was also reported as a barrier. In some areas minibus taxis refused to transport wheelchairs (Ntamo, Buso & Longo-Mbenza, 2013) . Walking or being pushed to healthcare facilities for rehabilitation was hampered by the unavailability of caregivers or accompanying persons (Grut et al., 2012) and geographical terrain, distance (Vergunst et al., 2015) and environmental factors (Scheffler et al., 2015) such as the weather. The time of day, week and year (De Klerk et al., 2019) were reported as barriers, an example being that appointments late in the day required service users to commute in the dark, thus exposing them to crime and dangers related to lack of sidewalks or lighting in public spaces.

The acceptability of rehabilitation services was affected by uniquely South African cultural (Vergunst et al., 2015) and belief (Wegner & Rhoda, 2015) systems causing barriers at user, provider and community levels (Schierenbeck et al., 2013) In some cases, rehabilitation service providers and general healthcare providers' attitudes were perceived to be rude and unacceptable (Ntamo et al., 2013). In South Africa, health science graduates complete a compulsory year of community service after graduation and many of them are placed in rural settings where they deliver a variety of services and work largely unsupervised (Ned et al., 2017) . The potential mismatch between levels of experience and responsibility could affect the rehabilitation experience of service users and providers. Stigmatisation experiences for persons with disabilities, from the general public (Cobbing et al., 2014) and public healthcare officials (Hussey et al., 2017) when attending rehabilitation, were reported as barriers. Rehabilitation users' frustration with long queues and waiting times to be seen by rehabilitation professionals (Kumurenzi et al., 2015) (Scheffler et al., 2015) (Vergunst et al., 2015) (Mutwali & Ross, 2019) affected service users' attitudes towards rehabilitation.

Additional barriers were disability related (Schierenbeck et al., 2013) (Cobbing et al., 2014) and included becoming easily fatigued, experiencing pain or public embarrassment while travelling or waiting for appointments. Not understanding rehabilitation services provided, and what they can offer, was also noted as a barrier (Grut et al., 2012) (Cobbing et al., 2014) (Moodley & Ross, 2015) (Naidoo & Ennion, 2019). Ineffective management, bureaucracy and lack of knowledge within public healthcare affected referrals and/or access to rehabilitation for persons with disabilities (Kumurenzi et al., 2015) (Hussey et al., 2017) . Language barriers between rehabilitation providers and users was a problem (Mlenzana et al., 2014) (Scheffler et al., 2015) (Hussey et al., 2017) (Naidoo & Ennion, 2019) specifically pertaining to cross-cultural understanding in rural contexts (Vergunst et al., 2015) and mental health rehabilitation (Schierenbeck et al., 2013) , .

Facilitators to Access Rehabilitation

Financial support offered by the government, mostly in the form of a disability or childcare grant, was reported to facilitate access to rehabilitation (Ntamo et al, 2013; (Maddocks, Moodley, Hanass-Hancock, Cobbing & Chetty, 2020)). Disability grants reduced persons with disabilities' feelings of being a burden on the family, as their grants were a source of income allowing them to support family members (Grut et al, 2012). Grants provided financial support, allowing persons with disabilities access to transport and rehabilitation; it also lifted their 'status' within families and communities as *breadwinners* (Mosoetsa, 2011). The South African social security grant system remains one of the few sources of social assistance for persons with disabilities within families living in poverty (McKenzie & Hanass-Hancock, 2017) and the single most effective poverty alleviator to date (Neves, Samson, van Niekerk, Hlatshwayo & du Toit., 2009) .

A positive rehabilitation experience (Cobbing et al, 2013; Kumurenzi et al, 2015; Scheffler et al, 2015; Naidoo & Ennion,2019) was also reported as a facilitator. Other facilitatory factors were decentralised healthcare facilities that offered multi-professional rehabilitation services (Grut et al, 2012; De Klerk et al, 2019), mobile health units that brought rehabilitation services to communities (instead of vice versa) (Vergunst et al, 2015), and healthcare facilities that were within walking distance (Scheffler et al, 2015; Mutwali & Ross, 2019). Persons with disabilities having a positive attitude towards rehabilitation and recovery was reported as a facilitator (Schierenbeck et al, 2013; Cobbing et al, 2014; Scheffler et al, 2015) that increased rehabilitation attendance. Having several reasons to attend a healthcare facility increased the attendance for rehabilitation and the reason for this was predominantly based on cost-saving considerations (Ntamo et al, 2013).

The most reported and discussed facilitator was the support of immediate (De Klerk et al, 2019) and extended family (Mlenzana et al, 2014; Hussey et al, 2017; Naidoo & Ennion, 2019), society and community (Kumurenzi et al, 2015; Morris et al, 2021) and religious communities (Maddocks et al, 2020), thus reflecting the concept of Ubuntu, which emphasises inter-connectedness, interdependence, and the importance of communal relationships (Joosub, 2019) This Pan-African philosophical framework was suggested as a support system to be utilised within the context of other vulnerable population groups, such as the elderly (van Biljon & van Niekerk, 2021). Such acceptance of interdependence, which in some cases would amount to dependence on others, might be seen in a negative light elsewhere, for example in European contexts (Ludvigsson, Wiklund, Swahnberg, & Simmons, 2022)where it has been reported as a dystopian role (Wilson, 2019). Conversely, interdependence is venerated and encouraged in African societies, one example being Archbishop Desmond Tutu who referred to it as *the essence of being human* (Tutu & Tutu, 2010).

Recommendations

Strategies to provide equitable, accessible, affordable, and evidence-based rehabilitation (Morris et al, 2021) were recommended by authors of the articles included in this scoping review. These included interdisciplinary rehabilitation approaches (Visagie & Swartz, 2016), the integration of existing skills and strategies of communities, persons with disability and their families (Grut et al, 2012), and collaboration with leaders within communities, including traditional healers and religious clerics (Joosub, 2019) The development of knowledge and an awareness within communities about disability rights (Hussey et al, 2017) in healthcare facilities, amongst caregivers (Naidoo & Ennion, 2019) and even persons with disabilities themselves, is needed. Calls were made for political and governmental action towards better recognition of rehabilitation as a human rights issue (Schierenbeck et al, 2013; Vergunst et al, 2015), the development of disability friendly healthcare policies (Moodley & Ross, 2015) and practical access support such as designated transport (Kumurenzi et al, 2015) for persons with disabilities to healthcare facilities.

Decentralising rehabilitation (Grut et al, 2012; Ntamo et al, 2013; Vergunst et al, 2015; Scheffler et al, 2015; Naidoo & Ennion, 2019), with a focus on community and home-based rehabilitation (Grut et al, 2012; Cobbing et al, 2014) interventions, was identified as a potential solution by authors. Equipping rehabilitation professionals with contextually relevant skills, (not only focusing on profession relevant skills) (Kritzinger, Schneider, Swartz & Braathen., 2014) Kumurenzi et al, 2015; Scheffler et al, 2015), was a further need that specifically pertained to community service practitioners (Wegner & Rhoda, 2015). Grut et al (2012) noted that community service practitioners, as a section of the South African rehabilitation workforce, can improve the distribution of rehabilitation. As such it is essential that graduates are trained and equipped for community-based rehabilitation to improve the quality of care and transfer of services to low-resourced areas. Wegner and Rhoda (2015) expanded on this, stating that it is important to educate and prepare rehabilitation service providers to be culturally aware, knowledgeable of and competent to meet the needs of rehabilitation service users, and especially so in rural contexts.

Rehabilitation practitioners are reminded to focus on client-centred approaches that allow participative decision making, considering the rehabilitation users' right of choice (Scheffler et al, 2015) – even within high-demand, busy and pressured practice settings. They are advised to foster good relationships with rehabilitation service users, and to educate, motivate, and encourage them (Naidoo & Ennion, 2019). Rehabilitation service providers should assist persons with disability to engage assertively within the health system (Kritzinger et al, 2014) to ask for what they need from rehabilitation services. To this end, they might need to understand better what rehabilitation can offer them. Comprehensive, individualised, non-discriminatory, and continuous care, based on good communication, respect and courteous interaction with service users (Scheffler et al, 2015), is required to ensure a positive and enjoyable experience for users.

Limitations

Barriers and facilitators should have been added to the search strategy and this oversight is acknowledged as a limitation of the review. The inclusion criteria could limit the transferability of evidence from this review to rehabilitation accesses outside of South Africa. Even within South Africa, studies showed differences between rural and urban access to rehabilitation, and it is suggested that such contexts be reviewed separately. Rehabilitation beyond healthcare was not considered, thus excluding services such as, for example, vocational rehabilitation and rehabilitation in schools.

CONCLUSION

South African persons with disabilities' access to rehabilitation in public healthcare facilities can be seen as a cauldron filled with a variety of inter-effecting issues of which history, poverty, location, limited resources, lack of knowledge and understanding, culture, and tradition are ingredients. Researchers, policymakers, rehabilitation service providers and other stakeholders such as families and organisations of persons with disabilities need to work together across scopes of practice and beyond the healthcare sector to improve access to their services. Efforts aimed at addressing access to rehabilitation services in South Africa's public healthcare, should take cognisance of facilitators that emanate from persons with disabilities and their communities. In addition, such efforts should include collaboration with community leaders, family members and, most importantly, persons with disabilities who are service users.

Acknowledgement

The authors acknowledge with gratitude the material and guidelines freely supplied by the Joanna Briggs Institute (JBI). The review and journal article contribute towards the degree award for authors MN, BS, JCvW, JD and LMK.

The affiliation of all authors is with Stellenbosch University.

Conflicts of interest, Funding and Bias Declarations

The authors declare that there is no bias affecting the interpretation and results of the review.

No sources of funding were received, and all expenses were covered by the authors' personal funds.

REFERENCES

Akter, S., Davies, K., Rich, J., & Inder, K. (2019). Indigenous women's access to maternal healthcare services in lower- and middle-income countries: a systematic integrative review. *International Journal of Public Health*, *64*(3), 343–353. https://doi.org/10.1007/s00038-018-1177-4. PMid:30506363

Bright, T., Wallace, S., & Kuper, H. (2018). A systematic review of access to rehabilitation for people with disabilities in low-and middle-income countries. *International Journal of Environmental Research and Public Health*, *15*(10), 1–34. https://doi.org/10.3390/ijerph15102165. PMid:30279358 PMCid:PMC6210163

Burger, R., Christian, C., & Burger R, C. C. (2020). Access to health care in post-apartheid South Africa: availability, affordability, acceptability. [Article]. *Health Econ Policy Law*, *15*(1), 43–55. https://doi.org/doi: 10.1017/S1744133118000300

Chiluba, B. C. (2019). Barriers to Health Care for Disabled People: A Review of the Literature from Low Income Countries. *Indonesian Journal of Disability Studies*, *6*(2 SE-Articles), 210–214. https://doi.org/10.21776/ub.IJDS.2019.006.02.11

Cobbing, S., Hanass-Hancock, J., & Deane, M. (2014). Physiotherapy rehabilitation in the context of HIV and disability in KwaZulu-Natal, South Africa. *Disability and Rehabilitation*, *36*(20), 1687–1694.https://doi.org/10.3109/09638288.2013.872199, PMid:24383469

De Klerk, S., Eloff, L., Naudé, Z., Boon, A., Carelse, M., Steward, M., & Zaidi, M. (2019). Non-attendance of occupational and physiotherapy appointments at Western Cape Rehabilitation Centre: a description of associated factors. *South African Journal of Occupational Therapy*, *49*(3), 54–63.https://doi.org/10.17159/2310-3833/2019/vol49n3a9

Evans, D. B., Hsu, J., & Boerma, T. (2013). *Universal Health Coverage and Universal Access*. https://doi.org/10.2471/BLT.13.125450, PMid:23940398 PMCid:PMC3738317

Gordon, T., Booysen, F., & Mbonigaba, J. (2020). Socio-economic inequalities in the multiple dimensions of access to healthcare: the case of South Africa. *BMC Public Health*, *20*(1), 289. https://doi.org/10.1186/s12889-020-8368-7, PMid:32131787 PMCid:PMC7057636

Grut, L., Mji, G., Braathen, S. H., & Ingstad, B. (2012). Accessing community health services: challenges faced by poor people with disabilities in a rural community in South Africa. *African Journal of Disability*, *1*(1), 1–7. https://doi.org/10.4102/ajod.v1i1.19, PMid:28729977 PMCid:PMC5442570

Hussey, M., MacLachlan, M., & Mji, G. (2017). Barriers to the implementation of the health and rehabilitation articles of the United Nations convention on the rights of persons with disabilities in South Africa. *International Journal of Health Policy and Management*, *6*(4), 207–218. https://doi.org/10.15171/ijhpm.2016.117, PMid:28812804 PMCid:PMC5384983

Joosub, N. (2019). How local context influences access to neuropsychological rehabilitation after acquired brain injury in South Africa. *BMJ Global Health*, *4*, 1–4. https://doi.org/10.1136/bmjgh-2018-001353,PMid:31799009 PMCid:PMC6861056

Kritzinger, J., Schneider, M., Swartz, L., & Braathen, S. H. (2014). "I just answer 'yes' to everything they say": Access to health care for deaf people in Worcester, South Africa and the politics of exclusion. *Patient Education and Counseling*, *94*(3), 379–383. https://doi.org/10.1016/j.pec.2013.12.006,PMid:24388666

Kumurenzi, A., Goliath, C., Mji, G., Mlenzana, N., Joseph, C., Stathum, S., & Rhoda, A. (2015). Experiences of patients and service providers with out-patient rehabilitation services in a rehabilitation centre in the Western Cape Province. *African Journal of Disability*, *4*(1), 1–7. https://doi.org/10.4102/ajod.v4i1.164, PMid:28730027 PMCid:PMC5433475

Ludvigsson, M., Wiklund, N., Swahnberg, K., & Simmons, J. (2022). Experiences of elder abuse: a qualitative study among victims in Sweden. *BMC Geriatrics*, *22*(1), 256. , https://doi.org/10.1186/s12877-022-02933-8, PMid:35351038 PMCid:PMC8962107

Maddocks, S., Moodley, K., Hanass-Hancock, J., Cobbing, S., & Chetty, V. (2020). Children living with HIV-related disabilities in a resource-poor community in South Africa: caregiver perceptions of caring and rehabilitation. *AIDS Care - Psychological and Socio-Medical Aspects of AIDS/HIV*, *32*(4), 471–479., https://doi.org/10.1080/09540121.2019.1654076, PMid:31426663

Maphumulo, W. T., & Bhengu, B. R. (2019). Challenges of quality improvement in the healthcare of South Africa post-apartheid: A critical review. *Curationis*, *42*(1), 1–9. https://doi.org/10.4102/curationis.v42i1.1901, PMid:31170800 PMCid:PMC6556866

McKenzie, T., & Hanass-Hancock, J. (2017). People with disabilities and income - related social protection measures in South Africa : where is the gap? *African Journal of Disability*, *6*(1), 1–11.https://doi.org/10.4102/ajod.v6i0.300

Meier, B. (2017). *Health and Human Rights*, World Health Organisation:World Report, *19*(1), 293–298. http://www.jstor.org.ez.sun.ac.za/stable/90007935

Mendeley Ltd. (2020). *Mendeley Reference Manager*. Elsevier.

Mlenzana, N., Eide, A., & Frantz, J. (2014). The profile and experiences of service providers with rehabilitation services in the Western Cape. *South African Journal of Physiotherapy*, *70*, 19+. https://doi.org/10.4102/sajp.v70i3.264

Moodley, J., & Ross, E. (2015). Inequities in health outcomes and access to health care in South Africa: a comparison between persons with and without disabilities. *Disability and Society*, *30*(4), 630–644.https://doi.org/10.1080/09687599.2015.1034846

Morris, L. D., Grimmer, K. A., Twizeyemariya, A., Coetzee, M., Leibbrandt, D. C., & Louw, Q. A. (2021). Health system challenges affecting rehabilitation services in South Africa [Article]. *Disability and Rehabilitation*, *43*(6), 877–883. https://doi.org/10.1080/09638288.2019.1641851, PMid:31378096

Mosoetsa, S. (2011). Eating from one pot: The dynamics of survival in poor South African households. In M. Wessels (Ed.), *NYU Press* (1st ed.). Wits University Press.https://doi.org/10.18772/12011045331

Mutwali, R., & Ross, E. (2019). Disparities in physical access and healthcare utilization among adults with and without disabilities in South Africa. *Disability and Health Journal*, *12*(1), 35–42. https://doi.org/10.1016/j.dhjo.2018.07.009, PMid:30082200

Myezwa, H., & Van Niekerk, M. (2013). National Health Insurance implications for rehabilitation professionals and service delivery. *South African Journal of Physiotherapy*, *69*(4), 3–9. https://doi.org/10.4102/sajp.v69i4.372

Naidoo, U., & Ennion, L. (2019). Barriers and facilitators to utilisation of rehabilitation services amongst persons with lower-limb amputations in a rural community in South Africa. *Prosthetics and Orthotics International*, *43*(1), 95–103.https://doi.org/10.1177/0309364618789457, PMid:30044179

National Department of Health. (2017). White Paper: National Health Insurance Policy - Towards Universal Health Coverage. *Department of Health*, 1–67.

Ned, L., Cloete, L., & Mji, G. (2017). The experiences and challenges faced by rehabilitation community service therapists within the South African Primary Healthcare health system. *African Journal of Disability*, *6*(1), 1–11.https://doi.org/10.4102/ajod.v6i0.311, PMid:29062760 PMCid:PMC5645568

Neille, J., & Penn, C. (2015). Beyond physical access: a qualitative analysis into the barriers to policy implementation and service provision experienced by persons with disabilities living in a rural context. *Rural and Remote Health*, *15*(3), 3332., https://doi.org/10.22605/RRH3332, PMid:26268958

Neves, D., Samson, M., van Niekerk, I., Hlatshwayo, S., & du Toit, A. (2009). The use and effectiveness of social grants in South Africa. *Institute for Poverty, Land and Agrarian Studies*, 1–110.

Ntamo, N. P., Buso, D., & Longo-Mbenza, B. (2013). Factors affecting poor attendance for outpatient physiotherapy by patients discharged from Mthatha general hospital with a stroke. *South African Journal of Physiotherapy*, *69*(3), 13–18.https://doi.org/10.4102/sajp.v69i3.29

Peters, M.D.J., Godfrey, C., McInerney, P., Baldini Soares, C., Khalil, H. and Parker, D. (2017). *Chapter 11: Scoping reviews. Joanna Briggs Institute Reviewer's Manual. The Joanna Briggs Institute (JBI).*

Rampin, R., Rampin, V., & DeMott, S. (2020). *Taguette Version 0.10.1*. Hi@taguette.Org.

Rayyan Sytems, I. (2020). *Rayyan Intelligent Sytematic Review*. Rayyan Https://Rayyan.Qcri.Org/.

Scheffler, E., Visagie, S., & Schneider, M. (2015). The impact of health service variables on healthcare access in a low resourced urban setting in the Western Cape, South Africa. *African Journal of Primary Health Care and Family Medicine*, *7*(1), 1–11.https://doi.org/10.4102/phcfm.v7i1.820, PMid:26245611 PMCid:PMC4656938

Schierenbeck, I., Johansson, P., Andersson, L., & van Rooyen, D. (2013). Barriers to accessing and receiving mental healthcare in Eastern Cape, South Africa. *Health and Human Rights*, *15*(2), 110–123.

The Constitution of the Republic of South Africa, Pub. L. No. The Bill of Rights, 243 (1996).

The National Health Act 61 of 2003, (2003).Government of South Africa.

Trani, J.-F., Bakhshi, P., Noor, A. A., Lopez, D., & Mashkoor, A. (2010). Poverty, vulnerability, and provision of healthcare in Afghanistan. *Social Science & Medicine*, *70* (11), 1745–1755. , h, https://doi.org/10.1016/j.socscimed.2010.02.007,PMid:20359809

Tricco AC, Lillie, E., Zarin, W., O'Brien, K., Colquhoun, H., Levac, D., Moher, D., Peters, M., Horsley, T., Weeks, L., Hempel, S., Akl, E., Chang, C., McGowan, J., Stewart, L., Hartling, L., Aldcroft, A., Wilson, M., Garritty, C., … Straus, S. (2018). PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. *Ann Intern Med*.https://doi.org/10.7326/M18-0850, PMid:30178033

van Biljon, H., & van Niekerk, L. (2021). Community Mobility and Transport Use of Urban Older Adults Who Attend Public Healthcare in Gauteng, South Africa. *South African Journal of Occupational Therapy*, *51*(3), 34–41. https://doi.org/10.17159/2310-3833/2021/vol51n3a5

van Gaans, D., & Dent, E. (2018). Issues of accessibility to health services by older Australians: a review. *Public Health Reviews*, *39*(1), 20. https://doi.org/10.1186/s40985-018-0097-4, PMid:30027001 PMCid:PMC6047130

van Stormbroek, K., & Buchanan, H. (2019). Novice occupational therapists: Navigating complex practice contexts in South Africa. *Australian Occupational Therapy Journal*, *66*(4), 469–481. https://doi.org/10.1111/1440-1630.12564, PMid:30697768

Vergunst, R., Swartz, L., Hem, K. G., Eide, A. H., Mannan, H., MacLachlan, M., Mji, G., Braathen, S. H., & Schneider, M. (2017). Access to health care for persons with disabilities in rural South Africa. *BMC Health Services Research*, *17*(1), 1–8.https://doi.org/10.1186/s12913-017-2674-5, PMid:29149852 PMCid:PMC5693516

Vergunst, R., Swartz, L., Mji, G., MacLachlan, & Mannan, H. (2015). "You must carry your wheelchair" - barriers to accessing healthcare in a South African rural area. *Global Health Action*, *8*(1), 1–8.https://doi.org/10.3402/gha.v8.29003, PMid:26434691 PMCid:PMC4592846

Visagie, S., & Swartz, L. (2016). Rural South Africans' rehabilitation experiences: Case studies from the Northern Cape Province. *South African Journal of Physiotherapy*, *72*(1), 1–8.https://doi.org/10.4102/sajp.v72i1.298, PMid:30135884 PMCid:PMC6093100

Wegner, L., & Rhoda, A. (2015). The influence of cultural beliefs on the utilisation of rehabilitation services in a rural South African context: Therapists' perspective. *African Journal of Disability*, *4*(1). https://doi.org/10.4102/ajod.v4i1.128, PMid:28730021 PMCid:PMC5433469

WHO and World Bank. (2011). *World report on disability*, Geneva

WHO (2001) International Classification of Functioning, Disability and Health (ICF), Geneva.

BRIEF REPORTS

Pushing Down the Walls: Advocating for "Rehabilitation for All" in South Africa

Saul Cobbing[1*], Bernhard Gaede [2], Theresa Lorenzo [3], Verusia Chetty[1]

1. Discipline of Physiotherapy, School of Health Sciences, University of KwaZulu-Natal, Durban, South Africa
2. Discipline of Family Medicine, School of Nursing and Public Health, University of KwaZulu-Natal, Durban South Africa
3. Division of Disability Studies, Department of Health and Rehabilitation Sciences, Faculty of Health Sciences, University of Cape Town, Cape Town, South Africa

ABSTRACT

This article aims to advocate for providing rehabilitation to all South Africans in the context of achieving universal health coverage. The potential benefits of accessible rehabilitation for South Africans with chronic disease and disability are described and supported by a description of national and international policies that promote the delivery of primary healthcare services (including rehabilitation) into or near people's homes. A discussion follows on why the 'walls' separating professional silos need to be broken down to ensure that rehabilitation can be provided in a cost-effective and sustainable manner. The authors also suggest ways in which advocacy efforts can be strengthened to assist in this call for "rehabilitation for all".

INTRODUCTION

Rehabilitation is a key component of healthcare which is extremely difficult for South Africans living in resource-poor communities to access, particularly if they are people with disabilities. These challenges have been exacerbated by the Covid-19 pandemic. In the context of planning the implementation of universal health coverage (UHC), it is time for rehabilitation practitioners, researchers, disability rights group and health activists to collectively initiate and strengthen advocacy efforts to ensure that "rehabilitation for all" becomes a reality, rather than a luxury service provided to those who can afford it. To achieve truly 'universal' UHC, a number of structural and resourcing barriers need to be pushed down; therefore this is a call for the re-establishment of training for, and recruitment of, mid-level rehabilitation workers to provide integrated rehabilitation services.

---

* **Corresponding Author:** Saul Cobbing, PhD, Discipline of Physiotherapy, School of Health Sciences, University of KwaZulu-Natal, Durban, South Africa. Email: cobbing@ukzn.ac.za

Providing Rehabilitation Services near People's Homes

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) defines disability as "long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder (an individual's) full and effective participation in society on an equal basis with others (United Nations, 2006). South Africa faces a quadruple burden of disease, which Mayosi et al (2012) describe as the four "colliding epidemics" of HIV/TB co-infection, maternal and child health, violence and injuries, and non-communicable diseases. Many people affected by each of these four epidemics should benefit from multi-faceted rehabilitation interventions that focus on maximising their mental and physical health. For example, while people living with HIV (PLHIV) in South Africa are living longer with the provision of free antiretroviral medication irrespective of CD4 count, they are also prone to developing a wide range of disabling conditions (Hanass-Hancock et al, 2015; Myezwa et al, 2018). There is evidence from local and international studies demonstrating that appropriate rehabilitation and exercise interventions can assist in improving the physical condition and quality of life of PLHIV (Gomes-Neto et al, 2013; Roos et al, 2014; O'Brien et al, 2016; Cobbing et al, 2017). Similarly, children with disability (e.g., cerebral palsy and developmental delay), victims of violence or accidents (e.g., traumatic brain injury and spinal cord injury) and people affected by non-communicable diseases (e.g., diabetes, obesity and various mental disorders) can all benefit from improved rehabilitation services. Due to the challenges in access and mobility for many people with disabilities, the services and care need to be provided as close to their homes as possible. While mortality and morbidity are recognised as the two established health indicators in the monitoring of any health system, functioning has recently been proposed as the *third* health indicator. Rehabilitation is vital for optimising functioning, by improving biological and mental health together with lived health (Stucki & Bickenbach, 2017). Simply put, while medical interventions (such as surgery and medication) can add years to life, rehabilitation can add quality of life to these additional years (Nixon et al, 2011).

The Current Situation in South Africa

In South Africa, however, there is a severe shortage of rehabilitation professionals. For example, there are approximately 3 physiotherapists per 10, 000 population in South Africa, as compared to 20 physiotherapists per 10, 000 population in

Finland, a country with a far lower burden of disease. Similarly, Denmark has approximately 11 occupational therapists per 10, 000 population, compared to less than 1 occupational therapist per 10, 000 population in South Africa (World Health Organisation, 2011). More recent WHO statistics show that Brazil, a country with a similar economy to South Africa, has almost three times more physiotherapists per head of population (World Health Organisation, 2016). Furthermore, the rehabilitation services that are there in the public healthcare sector are mainly based in urban hospitals and are very difficult for people in resource-poor, rural communities to access, particularly for those with disability (Gaede & Versteeg, 2011). South Africa's proposed UHC system, the National Health Insurance (NHI), promotes the rights of all South Africans to access quality healthcare services that "are affordable without exposing them to financial hardships" (Department of Health, 2015), while the White Paper on the Rights of Persons with Disabilities compels healthcare providers to ensure that treatment programmes are accessible to persons with disabilities (Department of Health,2016). This implies that the Department of Health is obligated to include rehabilitation services as part of 'universal' health care.

The Legal, Ethical and Economic Argument for providing Rehabilitation Services

A significant obstacle to implementing rehabilitation interventions and employing appropriate levels of rehabilitation workers in the South African public sector is adequate financing for rehabilitation services. This obstacle is particularly true in the current situation of national austerity, as evidenced by the freezing of healthcare posts across many of the provincial Departments of Health. It must be argued, however, that cost cannot preclude the provision of quality healthcare, as it is a fundamental human rights issue. From a legal perspective, South Africa is a signatory to several global conventions such as the CRPD (United Nations, 2006), which compels signatories to ensure that people with disabilities attain "full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life". The principle of progressive realisation in the CRPD requires not only that signatory countries provide the services and resources to ensure these rights, but also further entails a presumption against regressive measures that remove or reduce existing rights (Uldry & Deneger, 2018). South Africa also has several national policies that ensure the right of all of its citizens to equitable access to quality healthcare and support. These policies include the Batho Pele (People First) Principles (Department of Public Service and Administration, 1997) and the Framework and Strategy for Disability and Rehabilitation Services in South Africa (Department of Health, 2015). Key clauses within these policies highlight the fact that the provision of health services should be non-discriminatory, varied and flexible, and should take all necessary steps to include affected populations and local communities in the design and implementation of services.

Given the historical policies of South Africa pre-1994, which denied equitable healthcare to a majority of the population, it is evident how these post-apartheid policies are influenced by Section 27 of the Constitution (Republic of South Africa, 1996). The specific policies related to disability set out to ensure that this constitutional call was for *everyone* to have the right "access to healthcare services", including marginalised populations. It is also clear that legislative steps have been taken in South Africa to ensure this access extends to the large rural population. The National Development Plan (National Planning Commission, 2013), which espouses these views, contains the blueprint for the NHI, described above. The NHI stresses the provision of services to those most in need, rather than those with the most finances (Department of Health, 2015). This principle of equity implies clearly that people with disabilities should be prioritised (in terms of funding services for them) as their need is greater, particularly in the context where curative services have been disproportionately better funded. These new developments provide a great opportunity for rehabilitation professionals and other healthcare workers to be at the vanguard of promoting and supplying quality services to people with disability, many of whom live in impoverished, rural communities and cannot afford private healthcare. Furthermore, where these services are not being provided, health professionals now have an obligation to invoke specific legislative frameworks, such as those outlined above, within advocacy efforts aimed at redressing deficient systems. The challenge remains to translate these policies into practice. In addition to this, the training institutions need to design and implement programmes to build the capacity for an inclusive healthcare workforce to be able to meet the growing demand for rehabilitation services.

It is important, however, that advocacy efforts also extend beyond the human rights narrative to include pragmatic arguments that provide public health gatekeepers and stakeholders with evidence that complementary disability and rehabilitation interventions are beneficial for people with disabilities and their families, as well as potentially cost-effective for funders and taxpayers. Kaplan

(1999) states that costs and resources are often cited as limiting factors in achieving organisational success, as they are visible and easy to measure. However, Kaplan (1999) further argues that it is the intangible elements that actually contribute more to sustainability, such as an organisation's attitude (which includes social responsibility) and its vision and strategy. The authors of the current study propose, in the context of healthcare, that providing enhanced rehabilitation provision is not only the ethical thing to do but will also result in a number of long-term benefits for South Africa. There is evidence to show that rehabilitation services can contribute to cost savings in the longer term. For example, by focusing on people's functional and social needs, occupational therapy has been shown to decrease hospital re-admissions for several health conditions (Rogers et al, 2017). The World Health Organisation states, in its Rehabilitation 2030: Call for Action Report, that rehabilitation services are essential for economic and social development, particularly in low- and middle-income countries such as South Africa (WHO, 2017).

With respect to task-shifting for HIV care in Africa, Callaghan et al (2010) argue that task-shifting may not necessarily save costs but will ensure the long-term cost-effectiveness of interventions and sustainability. It is important that researchers develop approaches to measure the costs and benefits of novel interventions in comparison to standard practice, as well as more global returns on investment, in addition to assessing outcome measures of health, quality of life and function. The initiation of these interventions will further require committed government leadership and higher education institutes together with relevant professional bodies to provide training and funding, an eventuality that can be expedited by the generation of multi-faceted evidence and concerted advocacy efforts.

Strategies to Improve Rehabilitation Provision

An appropriate strategy to ensure improved access to rehabilitation could be the provision of these services close to, or in, people's homes to mitigate the environmental, physical and financial barriers that poor South Africans with disability face. Home-based rehabilitation (HBR) can be defined as any activities that prevent or treat an individual's impairments, activity limitations and participation restrictions, delivered in or near their own home (World Health Organisation, 2010). Local and international studies of home-based rehabilitation interventions for several chronic disease populations (Collins et al, 2001; Salvetti et al, 2008; Blair et al, 2011) have shown that these interventions are beneficial to recipients as well as equally cost-effective, if not more so, than traditional institution-based interventions. It should be noted that home-based rehabilitation is only one component of the more extensive community-based rehabilitation (CBR) guidelines, which encourage all stakeholders in health to focus on a broad range of educational, social and livelihood factors, underpinned by empowerment of all people with disabilities (World Health Organisation, 2010).

One way of ensuring that these criteria are met is to employ and train generalist rehabilitation workers in the public sector, who could assist people with disabilities in bridging the gap between health, schooling, work opportunities and social activities, including religious activities. In an effort to improve health promotion and disease prevention, the South African National Department of Health has promoted the deployment of ward-based outreach teams (WBOTs), comprising of six community health workers (CHWs) supervised by one nurse (Padayachee et al, 2013). While this initiative has shown some early success, Doherty et al (2016) argue that the role of the community health workers involved in this initiative is too narrow and their scope should be broadened to include curative functions. To achieve this, it is imperative that they be offered focused trans-professional training and structured career pathways that allow them the opportunity to upskill themselves and transition to mid-level workers.

By including community health workers who had received integrated rehabilitation training into these ward-based outreach teams, the rehabilitative options available to all people with disability in under-resourced communities would be increased. This task-shifting strategy may potentially reduce the cost burden to the public health service in the longer term, by ensuring that these individuals do not develop more severe disabilities that incur high treatment costs. By instituting task-shifting practices that are supported with appropriate training and supervision, productive efficiency of healthcare services can be achieved, while at the same time providing access to the best and most appropriate services that may otherwise not be available (Fulton et al, 2011). Task-shifting may address the current reality of rehabilitation services being unavailable to the vast majority of South Africans accessing the public healthcare sector.

Mid-level rehabilitation workers (MLRWs), known as community rehabilitation facilitators (CRFs) or community rehabilitation workers (CRWs) were trained in the 1990s/2000s, to provide integrated rehabilitation services in resource-poor communities (Hanass-Hancock et al, 2015). From 1991 to 2006 these CRFs/CRWs were recognised by the Occupational Therapy and Medical Orthotics / Prosthetics Board of the *Health Professions Council of South Africa (*HPCSA) and employed by the Departments of Health and Social Development across a number of provinces. They made a significant contribution in addressing the needs of people with disability close to their homes, across their life course (Rule et al, 2006). Despite this significant contribution over a period of 15 years, their registration with the HPCSA was discontinued from 2006 onwards. One of the key reasons cited for discontinuance was the negative intervention of professional rehabilitation groups. Chappell and Johannsmeier (2009) describe how the "professionalisation" of disability can result in a reduction of rehabilitation services. The professional protectionism and the resulting deregistration of CRFs/CRWs with the HPCSA in 2006 contributed to the cessation of the training and recruitment of mid-level rehabilitation workers in South Africa (Chappell & Johannsmeier, 2009). While they were offered the opportunity to retrain as occupational therapy technicians, which many of them took up, this change limited the broader empowerment role they had previously fulfilled and had a negative impact on people with disabilities. Evidence has shown that youth with disabilities in communities with continued input of CRWs have better access to health services and schooling than in communities without CRWs (Lorenzo et al, 2015).

Professionals in the rehabilitation field may see a new cohort of mid-level rehabilitation workers who provide integrated rehabilitation services as a threat to the traditional "professionally-siloed" scope of practice. Given the current austerity in the South African public healthcare sector, this may indeed be an understandable concern. However the opposite appears to be true, with increased referrals to health professionals reported when employing task-shifting strategies (Hugo, 2005). Evidence from South Africa highlights how the engagement and collaboration between community rehabilitation workers and final year occupational therapy students produced excellent outcomes, resulting in the removal of barriers to the participation of young people with disabilities in economic development (Denton et al, 2015). This evidence suggests that it is not a question of employing *either* professionals *or* community rehabilitation workers (CRWs) to provide rehabilitation services, but a clear need to employ more of *both* cadres of these workers, with clear delineation of tasks and referral systems in place between rehabilitation professionals and CRWs. To achieve truly 'universal' UHC, the authors of the present study are calling for the re-establishment of training and recognition of CRFS/CRWs. The emergence of a new mid-level healthcare cadre has recent precedent in South Africa. In 2002, an agreement was reached to train mid-level medical workers, known as clinical associates. The first cohort of clinical associates graduated in 2011 and quickly established themselves as important members of rural healthcare teams (Lorenzo et al, 2015). A similar recognition of mid-level rehabilitation workers can only occur if rehabilitation professionals move out of their professional silos and collaborate in designing and delivering new MLRW training programmes. It is also critical that CBR services and community-based health interventions focused on the quadruple burden of disease are meaningfully integrated – both in terms of service provisioning and clinical governance.

Strengthening Advocacy for "Rehabilitation for All"

The call for rehabilitation services to be made available to South Africans living in resource-poor communities on a sustainable basis needs to be amplified and taken up by Disabled People's Organisations, professional bodies, policy makers, health professionals, rehabilitation practitioners and civil society. The Rural Health Advocacy Project (RHAP) is a health advocacy organisation, advocating for equitable access to quality health care for South African rural communities (RHAP, 2018). One of their four main goals is to ensure an "equitable distribution of adequately trained, supported and caring healthcare workers to underserved rural areas". RHAP makes a strong argument against the reactive cutting of rehabilitation posts when budgets shrink. While health managers may see these services as "non-essential", this decision is a regressive choice, creating greater inefficiency and reduced access to services for the very people who need them most - people with disabilities, especially children and the elderly (RHAP, 2017).

It is crucial that healthcare workers and community members themselves become advocates for improved health services. By learning the key principles and commitments that are central to these global and national policies, healthcare workers can become strong advocates for marginalised groups in their communities. They can also then, in turn, provide communities and service users with the knowledge that will allow them to become activists for change, a process Heywood (2015) terms "tooling-up". RHAP offers clear advice to health science students, communities, and health professionals on how to "tool-up" and be better advocates for service users.

These education efforts must be extended to include staff involved in community-based rehabilitation programmes whose understandable focus on providing services has historically limited advocacy efforts (WHO, 2010). A collaboration of all interested parties can then collectively decide on how to approach stakeholders and gatekeepers to advocate for improved rehabilitation services. In the event of disinterest or disengagement from local or national stakeholders, the recourse for action in each specific policy should be invoked to ensure that advocacy efforts are maintained. Should these stakeholders agree to implement changes related to practice and resources, it is vital that they are presented with a clear description of what interventions are required, as well as a thorough plan related to their implementation. Dr Prinitha Pillay, while working as a facilitator for RHAP, argues: "Unless we act, and support those who do act, we risk allowing the unacceptable to become acceptable…if we want a different healthcare system, we cannot afford indifference" (Pillay et al, 2015).

In summary, the authors of the current study argue that rehabilitation services in South Africa are walled in behind current resource allocation and system functioning structures. They are walled in by funding, requiring a shift from prioritisation of curative services to equitable funding for rehabilitation services. They are walled in behind rural–urban and intra-urban inequity of resource allocation, requiring a shift toward prioritisation based on need. They are walled in behind professional silos (traditionally based on tertiary service delivery models), requiring a shift to a focus on providing integrated and coordinated care. These advocacy efforts need to focus on pushing down the walls to radically improve equitable rehabilitation services.

CONCLUSION

Rehabilitation needs to be viewed as a critical and essential necessity and not a luxury, with the potential to improve the physical health, functioning and quality of life of the most marginalised South Africans. To ensure access to rehabilitation for all South Africans, advocacy efforts from a wide range of stakeholders have to be stepped up. This advocacy needs to include calls for the implementation of novel evidence-based strategies, such as the renewed training, registration and employment of CRFs/CRWs, who have demonstrated the potential to be both clinically and financially effective in a time of austerity. It is vital that the reintroduction and design of new training programmes include the genuine participation of local communities. This will help to ensure that these programmes are designed to be both relevant to the people they are expected to benefit, as well as to the specific local context in which they will reside. It is vital that healthcare workers push down the walls that separate their professional silos and begin a genuine conversation that ensures that "rehabilitation for all", in the era of UHC, is a possibility rather than a pipe dream.

ACKNOWLEDGEMENT

This research is supported by UKZN's Developing Research Innovation, Localisation and Leadership in South Africa (DRILL) programme. This programme is funded by the Fogarty International Centre of the National Institutes of Health, under Award Number D43TW010131.

The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

REFERENCES

Blair, J., Corrigall, H., Angus, N. J., Thompson, D. R., & Leslie, S. (2011). Home versus hospital-based cardiac rehabilitation: a systematic review. *Rural and Remote Health*, *11*(2), 190-206. https://doi/10.3316/informit.343610641598918

Callaghan, M., Ford, N., & Schneider, H. (2010). A systematic review of task-shifting for HIV treatment and care in Africa. *Human resources for health*, *8*(1), 1-9. https://doi.org/10.1186/1478-4491-8-8, PMid:20356363 PMCid:PMC2873343

Chappell, P., & Johannsmeier, C. (2009). The impact of community based rehabilitation as implemented by community rehabilitation facilitators on people with disabilities, their families and communities within South Africa. *Disability and rehabilitation*, *31*(1), 7-13. https://doi.org/10.1080/09638280802280429, PMid:19194807

Cobbing, S., Hanass-Hancock, J., & Myezwa, H. (2017). A home-based rehabilitation intervention for adults living with HIV: A randomized controlled trial. *Journal of the Association of Nurses in AIDS Care*, *28*(1), 105-117. https://doi: 10.1016/j.jana.2016.08.008, PMid:27686717

Collins, L., Scuffham, P., & Gargett, S. (2001). Cost-analysis of gym-based versus home-based cardiac rehabilitation programs. *Australian Health Review*, *24*(1), 51-61. https://doi.org/10.1071/AH010051, PMid:11357742

Couper, I. D., & Hugo, J. F. (2014). Addressing the shortage of health professionals in South Africa through the development of a new cadre of health worker: the creation of Clinical Associates. *Rural and remote health*, *14*(3), 423-430. https://doi.org/10.22605/RRH2874

Denton, M., Brookman, C., Zeytinoglu, I., Plenderleith, J., & Barken, R. (2015). Task shifting in the provision of home and social care in O ntario, C anada: implications for quality of care. *Health & social care in the community*, *23*(5), 485-492. https://doi.org/10.1111/hsc.12168, PMid:25471361

Department of Health (2015). Framework and Strategy for Disability and Rehabilitation services in South Africa (2015-2020) [Internet]. Available from: ilifalabantwana.co.za/wp-content/uploads/2016/07/Framework-25-may_1_3.docx

Department of Health (2015). National Health Insurance for South Africa: Towards universal health coverage [Online]. Retrieved Sep 23, 2022, from https://www.health-e.org.za/wp-content/uploads/2015/12/National-Health-Insurance-for-South-Africa-White-Paper.pdf

Department of Health (2016). White Paper on the Rights of Persons with Disabilities [Online]. Retrieved Sep 23, 2022, from https://www.gov.za/sites/default/files/gcis_document/201603/39792gon230.pdf

Department of Public Service and Administration (1997). Batho Pele: White paper on Public Service Delivery [Online]. Retrieved Sep 23, 2022, from https://www.gov.za/documents/transforming-public-service-delivery-white-paper-batho-pele-white-paper

Doherty, T., Kroon, M., Rhoda, N., & Sanders, D. (2016). Ending preventable child deaths in South Africa: What role can ward-based outreach teams play? *South African Medical Journal*, *106*(7), 672-674. https://doi.org/10.7196/SAMJ.2016.v106i7.10790, PMid:27384356

Fulton, B. D., Scheffler, R. M., Sparkes, S. P., Auh, E. Y., Vujicic, M., & Soucat, A. (2011). Health workforce skill mix and task shifting in low income countries: a review of recent evidence. *Human resources for health*, *9*(1), 1-11. https://doi.org/10.1186/1478-4491-9-1, PMid:21223546 PMCid:PMC3027093

Gaede, B., & Versteeg, M. (2011). The state of the right to health in rural South Africa. *South African health review*, *2011*(1), 99-106.

Gomes-Neto, M., Conceicao, C. S., Carvalho, V. O., & Brites, C. (2013). A systematic review of the effects of different types of therapeutic exercise on physiologic and functional measurements in patients with HIV/AIDS. *Clinics*, *68*, 1157-1167. https://doi.org/10.6061/clinics/2013(08)16

Hanass-Hancock, J., Myezwa, H., & Carpenter, B. (2015). Disability and living with HIV: baseline from a cohort of people on long term ART in South Africa. *PloS one*, *10*(12), e0143936. https://doi.org/10.1371/journal.pone.0143936, PMid:26625001 PMCid:PMC4666651

Heywood, M. (2015). The treatment action campaign's quest for equality in HIV and health: learning from and lessons for the trade union movement. *Global Labour Journal*, *6*(3). https://doi.org/10.15173/glj.v6i3.2366

Hugo, J. (2005). Mid-level health workers in South Africa: not an easy option: human resources. *South African Health Review*, *2005*(1), 148-158.

Kaplan, A. (1999). Developingof Capacity: Community Development Resource Association. Cape Town: Centre for Developmental Practices. [Online]. Retrieved Sep 23, 2022, from

http://institutofonte.org.br/sites/default/files/Kaplan%20A_The%20Developing%20Of%20Capacity.pdf

Lorenzo, T., Motau, J., van der Merwe, T., Janse van Rensburg, E., & Cramm, J. M. (2015). Community rehabilitation workers as catalysts for disability: inclusive youth development through service learning. *Development in Practice*, *25*(1), 19-28. https://doi.org/10.1080/09614524.2015.983461

Mayosi, B. M., Lawn, J. E., Van Niekerk, A., Bradshaw, D., Karim, S. S. A., Coovadia, H. M., & Lancet South Africa team. (2012). Health in South Africa: changes and challenges since 2009. *The lancet*, *380*(9858), 2029-2043. https://doi.org/10.1016/S0140-6736(12)61814-5

Myezwa, H., Hanass-Hancock, J., Ajidahun, A. T., & Carpenter, B. (2018). Disability and health outcomes–from a cohort of people on long-term antiretroviral therapy. *SAHARA-J: Journal of Social Aspects of HIV/AIDS*, *15*(1), 50-59. https://doi.org/10.1080/17290376.2018.1459813, PMid:29635976 PMCid:PMC5917329

National Planning Commission (2013). National development plan vision 2030 [Online]. Retrieved Sep 23, 2022, from https://www.gov.za/sites/default/files/Executive%20Summary-NDP%202030%20-%20Our%20future%20-%20make%20it%20work.pdf

Nixon, S., Forman, L., Hanass-Hancock, J., Mac-Seing, M., Munyanukato, N., Myezwa, H., & Retis, C. (2011). Rehabilitation: a crucial component in the future of HIV care and support: opinion. *Southern African Journal of HIV Medicine*, *12*(2), 12-17. https://doi.org/10.4102/sajhivmed.v12i2.191

O'Brien, K. K., Tynan, A. M., Nixon, S. A., & Glazier, R. H. (2016). Effectiveness of aerobic exercise for adults living with HIV: systematic review and meta-analysis using the Cochrane Collaboration protocol. *BMC infectious diseases*, *16*(1), 1-56. https://doi.org/10.1186/s12879-016-1478-2, PMid:27112335 PMCid:PMC4845358

Padayachee, T., Chetty, N., Matse, M., Mampe, T., & Schneider, H. (2013). Progress in the establishment of ward-based outreach teams: experiences in the North West Province. *South African health review*, *2013*(1), 73-79.

Pillay, P. (2015). Resuscitating an ethical climate in the health system: The role of healthcare workers. *South African Medical Journal*, *105*(4), 277-278. https://doi.org/10.7196/SAMJ.9397, PMid:26294867

Republic of South Africa (1996). Constitution of the Republic of South Africa, Act 108 of 1996 [Online]. Retrieved Sep 23, 2022, from http://www.gov.za/sites/www.gov.za/files/images/a108-96.pdf

Rogers, A. T., Bai, G., Lavin, R. A., & Anderson, G. F. (2017). Higher hospital spending on occupational therapy is associated with lower readmission rates. *Medical Care Research and Review*, *74*(6), 668-686. https://doi.org/10.1177/1077558716666981, PMid:27589987

Roos, R., Myezwa, H., van Aswegen, H., & Musenge, E. (2014). Effects of an education and home-based pedometer walking program on ischemic heart disease risk factors in people infected with HIV: a randomized trial. *JAIDS Journal of Acquired Immune Deficiency Syndromes*, *67*(3), 268-276. https://doi.org/10.1097/QAI.0000000000000299, PMid:25140908

Rule, S., Lorenzo, T., Wolmarans, M., Watermeyer, B., Swartz, L., & Lorenzo, T. (2006). Community-based rehabilitation: new challenges. *Disability and social change: A South African agenda* (pp. 273-290). HSRC Press.

Rural Health Advocacy Project - RHAP (2017). Cutting Human Resources for Health: Who pays? [Online]. Retrieved Sep 23, 2022, from http://rhap.org.za/cutting-human-resources-health-pays/

Rural Health Advocacy Project - RHAP (2018). [Online]. Retrieved Sep 23, 2022, from http://rhap.org.za/

Salvetti, X. M., Oliveira, J. A., Servantes, D. M., & Vincenzo de Paola, A. A. (2008). How much do the benefits cost? Effects of a home-based training programme on cardiovascular fitness, quality of life, programme cost and adherence for patients with coronary disease. *Clinical Rehabilitation*, *22*(10-11), 987-996. https://doi.org/10.1177/0269215508093331, PMid:18955430

Stucki, G., & Bickenbach, J. (2017). Functioning: the third health indicator in the health system and the key indicator for rehabilitation. *European journal of physical and rehabilitation medicine*, *53*(1), 134-138. https://doi.org/10.23736/S1973-9087.17.04565-8

Uldry M, Deneger T (2018). Towards inclusive equality: 10 years Committee on the Rights of Persons with Disabilities [Online]. Retrieved Sep 23, 2022, from https://tbinternet.ohchr.org/Treaties/CRPD/Shared%20Documents/1_Global/INT_CRPD_INF_21_28325_E.pdf

United Nations (2006). United Nations Convention on the Rights of Persons with Disabilities [Online]. Retrieved Sep 23, 2022, from https://treaties.un.org/doc/Publication/CTC/Ch_IV_15.pdf

World Health Organisation (2010). Community-based rehabilitation: CBR Guidelines [Online]. Retrieved Sep 23, 2022, from http://www.who.int/disabilities/cbr/guidelines/en/

World Health Organisation and World Bank (2011). World report on disability [Internet]. World Health Organisation. Available from: http://www.who.int/disabilities/world_report/2011/report.pdf

World Health Organisation (2016). Global atlas of the health workforce [Online]. Retrieved Sep 23, 2022, from https://www.who.int/data/gho/data/themes/topics/health-workforce

World Health Organisation (2017). Rehabilitation 2030: A call for action: Meeting report [Online]. Retrieved Sep 23, 2022, from https://www.who.int/publications/m/item/rehabilitation-2030-a-call-for-action

CASE STUDIES

Outcomes of Cognitive-Communication Intervention in Traumatic Brain Injury: a Case Study

Vinitha Mary George*

ABSTRACT

Purpose: *Traumatic brain injury (TBI) is an acquired non-progressive condition, resulting in distinct deficits of cognitive communication abilities such as naming, word-finding, self-monitoring, auditory recognition, attention, perception and memory. Cognitive-communication intervention in TBI is individualised, in order to enhance the person's ability to process and interpret information for better functioning in family and community life. The present case study illustrates the cognitive-communicative disturbances secondary to TBI and its intervention outcomes in a female adult in India.*

Method: *The 43-year-old subject attended 20 sessions of cognitive-communication intervention which followed a domain-general adaptive training paradigm, with tasks relevant to everyday cognitive-communication skills.*

Results: *Improvements were found in perception, short-term and working memory, with reduction in perseverations and naming difficulties.*

Conclusion: *Rehabilitation of clients with moderate to severe head injury can be done effectively through the appropriate selection of goals and activities relevant to the functional needs of each individual.*

Key words: traumatic brain injury, cognitive-communication, perception, memory, rehabilitation

INTRODUCTION

Communication is an overall socially distributed cognitive activity, which incorporates the perception, analysis and execution of information in not just an isolated environment but in a dynamic one which requires coordination at various

---

* **Corresponding Author:** National Institute of Speech and Hearing, Thiruvananthapuram, India.
Email: vinithageorge@nish.ac.in

levels, thus making cognition a key feature for basic living and communication (Harris, 2006). The relation between cognition and language is intricate, requires perception, access to long-term memory, association, recognition, attention, lexical retrieval, decision making, motor planning, self-monitoring, and knowledge (MacDonald et al, 2001).

Cognitive-communication disorders are difficulties in various communicative competencies that result from underlying cognitive impairments of attention, memory, organisation, information processing, problem solving, and executive functions (Togher et al, 2013). Traumatic brain injury (TBI) is the largest and most documented condition, with acquired non-progressive brain injury resulting in distinct cognitive communication disorders. The consequences of TBI, in the acute phase and in later stages, depend on the type of trauma, the severity, location, and extent of the brain injury. Traumatic brain injury can affect any area of the brain, and usually more than one area. Communication becomes dysfunctional, inadequate and sometimes ineffective, with difficulties in understanding and producing gestures and facial expressions appropriately; recognising the prosodic aspects of speech; maintaining eye contact; initiating, maintaining or changing the topic of conversation appropriately; adapting vocabulary to different everyday contexts; organising discourse coherently and cohesively; respecting communication shifts; understanding the interlocutor's needs; getting lost in irrelevant comments and uninteresting details; and, inability to make inferences from long and complex content. There is also inability to understand sarcastic utterances or situations where a sense of humour is involved, and sometimes the display of reduced initiative and communicative inhibition/disinhibition (Togher et al, 2013; McDonald et al, 2016). Brain-injured clients may exhibit symptoms such as naming errors, word-finding problems, impaired self-monitoring, and auditory recognition impairments along with other cognitive-communication impairments, such as attention and perception difficulties and impaired memory (Kennedy et al, 1995; Kim et al, 2009; Felix et al, 2019).

For persons with TBI, cognitive rehabilitation — a clinical discipline that encompasses interdisciplinary activity aiming at recovery and compensation of cognitive processes changed by cerebral injury — is crucial. An individual's ability to process, interpret, and respond appropriately to environmental inputs is recovered through a cognitive rehabilitation programme. Additionally, strategies and procedures are developed to make up for lost abilities that are required in interpersonal, social, educational, and professional relationships

(Freire et al, 2011). Although there are many different strategies used in cognitive rehabilitation, it is generally agreed in the literature that each client's needs must be considered.

Studies have distinguished two parts of cognitive rehabilitation therapy: an approach that is restorative and one that is compensating. The goal of the restorative method is to improve, reinforce, or restore the compromised skills. It involves retaking standardised cognitive tests that are harder each time, focusing on certain cognitive domains (e.g., selective attention, memory for new information). The compensatory method teaches strategies for avoiding or making up for the dysfunctional function. The efficient use of assistive technologies (ATs), calendars, electronic memory devices, alarms or reminders, as compensatory approaches, has been documented by a number of authors (Shoulson et al, 2012; Barman et al, 2016). Despite the various efforts to evaluate the effectiveness of cognitive rehabilitation, a clear lack of understanding the exact nature, theory and rationale of the cognitive intervention has been noted (Shoulson et al, 2012).

Speech-language pathologists play a primary role in the screening, assessment, diagnosis, and treatment of infants, children, adolescents, and adults with cognitive-communication disorders. The following case report illustrates the cognitive-communicative behaviours and the management outcomes of an individual with TBI.

METHOD

Case Presentation

A 43-year-old female, a known case of traumatic brain injury consequent to a road traffic accident, was brought to the Department of Audiology and Speech Language Pathology, KMCH, India?, with disturbances in cognitive communicative abilities. Due to the accident, the client had suffered head and facial injuries and fracture of both the forearms. No sensory deficits were present except for a slight vision problem in the left eye due to post- traumatic keratosis. Neurological evaluation was done, and the CT scan revealed bilateral frontal subdural hygroma with significant resolution of bilateral frontal region and left preseptal extra calvarial soft tissue swelling.

Cognitive Communicative Skills

A detailed cognitive communication assessment, which was done informally, revealed the client to have severe naming deficits along with perseverations, deficits in episodic memory (such as recalling the details of the accident and the places she had visited earlier), deficits in short-term memory and semantic memory (such as difficulty recalling her house address, names of people known to her, as well as the activities she did each day), leading to severe breakdowns in her communicative abilities. On administration of the Mini Mental State Examination (Folstein et al, 1975) and the Manipal Manual of Cognitive Linguistic Abilities (Mathew et al, 2013) it was noted that the client lacked orientation to time and space, while the other cognitive-communicative processes which were seen to be affected included attention, visual and auditory perception, working memory and executive functions, with reasoning abilities remaining intact. The client had difficulty in engaging in conversation with family members as well as friends. Topic initiation and maintenance was severely affected. The client lacked self-awareness and self-monitoring abilities which hindered the application of any form of communication repair strategies. Spontaneous speech, automated speech and repetition skills, which were assessed informally, were noted to be intact.

The baseline pre-therapeutic cognitive-communication skills assessed using the Manipal Manual of Cognitive Linguistic Abilities (MMCLA) (Mathew et al, 2013) revealed poor performance scores on perception, short-term memory, and working memory (as shown in Table 1). Cognitive-communication intervention was recommended thrice a week, with each session to be of one-hour duration.

Table 1: Pre-therapeutic Baseline Scores on MMCLA

Perception	**Pre-therapy Scores (accuracy)**
Auditory letter and word search	7/17
Visual letter search	9/15
Visual picture and number search	1/10
Visual action and feature search	2/10
Short-term memory and Working memory	
Auditory word retrieval	9/20
Auditory word list recall	6/15

Intervention

The client attended cognitive communication intervention thrice a week, for a period of two months, with each session of one-hour duration. The intervention (see Table 2) followed a domain-general, adaptive training paradigm, with tasks relevant to everyday cognitive-communication skills. The client was engaged in general conversation at the beginning of each session, followed by structured therapy tasks targeting various cognitive communication skills, such as name and object recall, sequencing events, letter and categorical free recall of words, and digit and month ordering. The stimuli for these tasks were arranged in a hierarchical order of complexity and were provided in the auditory, visual and/ or auditory-visual combined modalities. For every complexity level, 10 sets of stimuli for each task were given for practice in each session. The training moved to the next higher level of complexity only with a consistent progress of 80% accuracy in the targeted level of complexity. Feedback was given after every response.

Table 2: Details of the Structured Intervention

Task	Stimuli	Description	Complexity range (in span/steps)	Stimulus duration	Inter-stimulus duration	Modality	Intervention approach
Name recall	Series of names of persons	You will be presented with a series of names in a simultaneous auditory-visual modality. You are required to remember these names and recall them verbally in any order when the response screen appears.	2-7	2000ms	1000ms	Auditory-Visual	Domain-general, adaptive training paradigm
Object recall	Series of common everyday objects	You will be presented with a series of pictures of common objects in a visual modality. You are required to remember these objects and recall them verbally in any order when the response screen appears.	2-7	2000ms	1000ms	Visual	
Letter and category free recall of words	K, D, S, household objects, body parts, places, animals, fruits	You have to verbally recall as many words as possible which begin with the specified letters and which belong to the specified categories.	Not applicable	Not applicable	Not applicable	Auditory	-

Digit ordering	Series of single digits	You will be presented with a series of single digits in a simultaneous auditory-visual modality. You are required to remember these digits and recall them verbally in ascending order when the response screen appears.	2-7	2000ms	1000ms	Auditory-Visual	Domain-general, adaptive training paradigm
Month ordering	Series of months	You will be presented with a series of months in a simultaneous auditory-visual modality. You are required to remember these months and recall them verbally in any order when the response screen appears.	2-7	2000ms	1000ms	Auditory-Visual	
Sequencing	Everyday tasks (e.g., making a cup of tea)	You will be shown jumbled pictures of action steps for a task and you are required to rearrange them in the correct sequence.	2-5	Not applicable	Not applicable	Visual	

Apart from the structured therapy tasks, certain other activities and games targeting various cognitive-communicative processes were incorporated in the therapy sessions, such as singing games to improve short-term and long-term memory, and auditory perception, spotting the difference to improve visual perception and attention, recalling cooking recipes and planning monthly household needs and budget to improve executive functions. Compensatory strategies were also recommended, by involving the family members in assisting the client to maintain a diary with reminders of daily routine and names of people, use of calendars and alarms for orientation to days, time and place.

RESULTS

Post-therapeutic assessment was done by re-administering the MMCLA and improvements in the performance scores were noted for auditory and visual perception, short-term memory and working memory (as shown in Table 3).

Table 3: Post- therapeutic Scores on MMCLA

Perception	**Post-therapy Scores (accuracy)**
Auditory letter and word search	10/17
Visual letter search	12/15
Visual picture and number search	9/10
Visual action and feature search	6/10
Short-term memory and Working memory	
Auditory word retrieval	13/20
Auditory word list recall	10/15

Improvements were also noted on some of the trained cognitive-communication task performances (as shown in Table 4).

Table 4: Performance on the Trained Cognitive-Communication Tasks

Task	**Baseline Performance**	**Post-therapy Performance**
Digit ordering	**Accuracy**	**Accuracy**
3 span	50%	100%
4 span	0%	100%
Object recall		
3 span	40%	100%
4 span	0%	80%
Sequencing		
3 step	50%	80%
5 step	0%	60%
Free recall	**Number of items recalled**	**Number of items recalled**
Letter K	1 word	4 words
D	2 words	7 words
S	2 words	6 words
Category	**Number of items recalled**	**Number of items recalled**
Household objects	3	8
Body parts	5	9
Places	3	8
Animals	5	6
Fruits	2	6

The frequency of perseverations significantly reduced. The accuracy of correct responses increased with practice. The client also developed interest in independently initiating her day-to-day activities at home as well as involving in conversations with her family members and friends. Though she continued to lack awareness about her deficits, her involvement in the therapeutic activities was noteworthy.

DISCUSSION

Following a TBI, the goal of cognitive communication rehabilitation is to increase the person's ability to absorb and comprehend information as well as to perform tasks requiring mental operations (Barman et al, 2016). A systematic approach towards intervention designs to improve cognitive abilities and their application to normal everyday activities is essentially incorporated in cognitive rehabilitation (Wortzel & Arciniegas, 2012).

The interventions mainly aim at re-establishing or reinforcing the previously learned skills which include repeated exercise of tasks, increasing in complexity, and those targeting certain cognitive domains, developing compensatory strategies for cognitive deficits such as use of electronic memory devices, calendars and alarms, and/or facilitating adaptation to irremediable cognitive impairments (Koehler et al, 2012).Cognitive communication rehabilitation includes the parameters of general interventions which target a range of cognitive processes, and cognitive specific interventions which target a specific cognitive process such as memory or attention (Sanjuán et al, 2020; Gray et al, 2022). Much remains to be learned about the kinds of training programmes that provide meaningful changes beyond the specific skills trained. Cognitive-communicative training will be deemed useful if the training has generalised benefits and builds cognitive capacities to support performance in day-to-day tasks (Chapman & Mudar, 2014).

CONCLUSION

Rehabilitation of moderate to severe head injury clients can be done effectively through holistic cognitive retraining. Hierarchically arranged modules that focus on different cognitive domains in all the modalities form the basis of such programmes. Clients move through these domains at their own pace while mastering each one. Selection of goals and preparation of activities and tasks should be in relevance to the functional needs of each individual with TBI, as highlighted in the present case report. Compliance of the client, support of the family and long-term follow up are essential for these extensive procedures to be beneficial.

REFERENCES

Barman, A., Chatterjee, A., & Bhide, R. (2016). Cognitive impairment and rehabilitation strategies after traumatic brain injury. *Indian Journal of Psychological Medicine*, *38*(3), 172-181. https://doi.org/10.4103/0253-7176.183086,PMid:27335510 PMCid:PMC4904751

Chapman, S. B., & Mudar, R. A. (2014). Enhancement of cognitive and neural functions through complex reasoning training: evidence from normal and clinical populations. *Frontiers in Systems Neuroscience*, *8*, 69. https://doi.org/10.3389/fnsys.2014.00069

Felix, F., Varghese, A., & Kumaraswamy, S. (2019). An Objective Measure of Naming Errors in Individuals with Traumatic Brain Injury. *Language in India*, *19*(5).

Folstein, M. F., Folstein, S. E., & McHugh, P. R. (1975). Mini-mental state: A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research*, *12*, 189-198. https://doi.org/10.1016/0022-3956(75)90026-6

Freire, F. R., Coelho, F., Lacerda, J. R., Silva, M. F. D., Gonçalves, V. T., Machado, S., Velasques, B., Ribeiro, P., Basile, L. F. H., Oliveira, A., Paiva, W., Kanda, P., & Anghinah, R. (2011). Cognitive rehabilitation following traumatic brain injury. *Dementia & Neuropsychologia, 5*, 17-25. https://doi.org/10.1590/S1980-57642011DN05010004, PMid:29213715 PMCid:PMC5619134

Gray, N., Yoon, J. S., Charness, N., Boot, W. R., Roque, N. A,, Andringa, R., Harrell, E. R., Lewis, K. G., & Vitale, T. (2022). Relative effectiveness of general versus specific cognitive training for aging adults. *Psychology and Aging, 37*(2), 210. https://doi.org/10.1037/pag0000663, PMid:34968102

Harris, C. L. (2006). Language and cognition. *Encyclopedia of cognitive science*, 1-6. https://doi.org/10.1002/0470018860.s00559

Kennedy, M. R., Yorkston, K. M., Rogers, M. (1995). Self-monitoring abilities of two adults with traumatic brain injury during verbal learning. *American Journal of Speech-Language Pathology*, *4*(4), 159-163. https://doi.org/10.1044/1058-0360.0404.159

Kim, J. S., Kim, O. L., Seo, W. S., Koo, B. H., Joo, Y., & Bai, D. S. (2009). Memory dysfunctions after mild and moderate traumatic brain injury: comparison between patients with and without frontal lobe injury. *Journal of Korean Neurosurgical Society*, *46*(5), 459. https://doi.org/10.3340/jkns.2009.46.5.459, PMid:20041056 PMCid:PMC2796352

MacDonald, M. C., Almor, A., Henderson, V. W., Kempler, D., Andersen, E. S. (2001). Assessing working memory and language comprehension in Alzheimer's disease. *Brain and Language, 78*(1), 17-42. https://doi.org/10.1006/brln.2000.2436, PMid:11412013

Mathew, M. M., Bhat, J. S., Sreya, N. M., & Arora, A. (2013). *Manipal Manual of Cognitive Linguistic Abilities*. Manipal University press, India.

McDonald, S., Code, C., & Togher, L. (2016). *Communication disorders following traumatic brain injury*. Psychology press. https://doi.org/10.4324/9781315539034

Sanjuán, M., Navarro, E., & Calero, M. D. (2020). Effectiveness of cognitive interventions in older adults: a review. *European Journal of Investigation in Health, Psychology and Education, 10*(3), 876-898. https://doi.org/10.3390/ejihpe10030063, PMid:34542517 PMCid:PMC8314287

Shoulson, I., Wilhelm, E. E., & Koehler, R. (Ed.) (2012). Cognitive rehabilitation therapy for traumatic brain injury: evaluating the evidence. National Academies Press. http://elibrary.pcu.edu.ph:9000/digi/NA02/2011/13220.pdf

Togher, L., McDonald, S., Coelho, C. A., Byom, L. (2013). Cognitive communication disability following TBI: examining discourse, pragmatics, behaviour and executive function. In S. McDonald, L. Togher, & C. Code, *Social and communication disorders following traumatic brain injury* (pp. 89-118). Psychology Press.

Wortzel, H. S., & Arciniegas, D. B. (2012). Treatment of post-traumatic cognitive impairments. *Current Treatment Options in Neurology*, 14(5), 493-508. https://doi.org/10.1007/s11940-012-0193-6, PMid:22865461 PMCid:PMC3437653

LETTER TO EDITOR

Dear Editor,

Inclusive Education in Pakistan: Role of Teachers’ Sense of Self-Efficacy

The worldwide inclination toward inclusive education has made it possible for children with disability to be included in mainstream schools (Ozokcu, 2018). Inclusive education is regarded as a transformation that intends to remove all obstacles to the inclusion of every learner into the mainstream school system, irrespective of their disability (Hamenoo & Dayan, 2021). The idea of inclusion reflects a thoughtful approach that accepts, respects, and values diversity and differences among all individuals. It also targets the development of school systems for every individual (Ghosh, 2022). The drive toward inclusive education lays stress on teaching children with disabilities in regular classrooms. The current reauthorization of the Individuals with Disabilities Education Act (IDEA, 1997) also includes wide-ranging provisions that boost the enrolment of students with disabilities in inclusive classrooms.

According to Bandura’s Self-Efficacy Theory (1977), “[it is] an individual’s belief in his or her capacity to execute behaviors necessary to produce specific performance attainments. Self-efficacy reflects confidence in the ability to exert control over one’s motivation, behavior, and social environment”. The teacher’s belief signifies a vital variable in discovering the effective execution of an inclusive course of action. Also, the teacher’s opinion plays a pivotal role in catering to disabilities and it has a direct influence on students’ learning and development (Raath & Hay, 2016). The role of teachers in inclusive educational settings differs from their conventional role. Regular school teachers must be aware of the variety of contemporary classroom setups and must be able to modify their instructional plans following the diversity of learning styles within the classroom (Abbas, Zafar, & Naz, 2016).

Hameed and Manzoor (2019) stated that it is generally observed that teachers face increased stress as their roles diversify and they become reluctant to cater to disabilities. Many teachers working in inclusive as well as non-inclusive schools lack preparation to teach children with disabilities (Shaukat & Rasheed, 2015). Previous research studies showed that while teachers support inclusive educational settings, they are often not confident about teaching children with disabilities, using appropriate resources and managing classrooms (Khan & Behlol, 2014). Therefore, it is very important to know the relationship between teachers' sense of self-efficacy and their opinions, as it helps to determine the role of teachers' self-awareness in promoting inclusive education (Ghosh, 2022).

We conducted a research study that examined the correlation between the teachers' sense of self-efficacy for an inclusive classroom setup and their opinions regarding the inclusion of children with special educational needs in a regular school setting. It is important to understand that in Pakistan the terms 'children with special educational needs' and 'children with disabilities' are often used interchangeably. The findings of the research study showed a significant positive relationship between the teachers' opinions about inclusion and the promotion of inclusive settings in schools. Positive opinions of teachers create the foundation for inclusive educational practices. In this regard, a positive school ethos and positive attitudes among the workforce are factors that make a significant contribution to successful inclusion.

The data analysis in the current study also revealed that the teachers' sense of self-efficacy offers complementary mediation between their opinions about inclusion and inclusive settings in schools. Therefore, the teachers' confidence proved to be a significant construct in expressing teachers' positive attitudes to promote inclusion. This finding is consistent with that of other research studies carried out, including Ozokcu (2018) and Dalanon and Matsuka (2017). The findings from previous research studies proposed that teachers' acceptance of the presence of children with special educational needs is among the key predictors of positive attitudes concerning their inclusion of them.

Bandura (1977) found that teachers who have an act of courage and assertiveness demonstrate greater levels of organizational planning, maintain self-confidence and enthusiasm, and are more capable of coping with their stress and negative opinions. Sharma, Simi, and Forlin (2015) stated that teacher's belief in themselves is a significant factor that is found to affect the instructional practices of teachers in inclusive classroom setups. This self-confidence is of major importance for the success of inclusive practice within mainstream classrooms. The present research study suggests that teachers with a greater belief in their ability are usually keen to try out new techniques that cater to the requirements of their students with disability. Keeping in view the growing demand for implementing inclusive educational practices and, above all, Pakistan being a signatory to Sustainable Development Goals, this letter to the Editor provides a recommendation to meet the demands of Sustainable Development Goals. The Sustainable Development Goal (SDG 4) highlights the provision of inclusive and equitable quality education for all. It also emphasizes eliminating all differences in education and ensuring the inclusion of persons with disabilities (United Nations, 2015).

The study findings point towards some indicators that can make inclusive education more effective.

Increasing the level of self-efficacy of teachers

- Professional development: The study found that a teacher's self-motivation is regarded as an imperative element in terms of supporting the idea of inclusive instructional practices. Hence, teacher education programs can be effective in increasing teachers' efficiency. This can be achieved through pre-service and in-service training programs for engaging with children with special educational needs. Self-confidence in instructional approaches, learner engagement, and classroom management are needed for successful teaching and learning. Investing in teacher education programs is recommended as this can have a positive impact on the development of a country's human resources. Professional development courses enable teachers to develop the necessary competencies to teach children with special educational needs. Developing their confidence can be a means of enhancing teachers' self-efficacy. Therefore continuous professional development is needed.
- Training workshops: In addition, the research study indicated that collaboration among different stakeholders through training workshops can play a pivotal role in boosting confidence, thus enhancing self-efficacy.
- Curriculum development: There is a need to put more effort into the provision of pertinent human and material resources. The material resources includes relevant teaching material and teaching strategies in the curriculum. The curriculum must be designed to support teachers in imparting pedagogical practices to facilitate children with special educational needs.

Increasing the collaboration among stakeholders

- Collaboration among teachers: The concept of collaborative teaching is a need of the day. For this, teachers must share their experiences with one another. The teachers who are catering to children with special educational needs must train those who are not teaching such children. This can be a means of increasing self-confidence as the teacher's poise enables the students to perform effectively. This can be organized in the form of an in-service development course in which competencies can be fostered that are necessary to educate students with disabilities. The teacher-to-teacher interaction can play a vital role in the effective execution of inclusive educational practices

- Collaboration among teachers and school leadership: If the leadership of schools, are willing to achieve the Sustainable Development Goal of having inclusive schools, then they should work towards providing opportunities for professional development of teachers; this can pave the way towards inclusive settings in schools. The school must include classroom teachers in all phases of inclusive policy development. There is a need to improve the quality of instructional techniques and the provision of material resources. The curriculum must be designed in such a way that it enables teachers to feel equipped with knowledge, skills, and right attitudes to support children with disabilities.
- Collaboration with policymakers: The government should establish more professional development organizations for preparing teachers to enable the effective implementation of inclusive practices. A support mechanism must be provided that encourages transformation in attitudes, opinions, morals, and behavior. The major issues identified in this research study – with regard to teachers' professional development, student requirements, and resources - are vital for successful inclusive practices. The current pre-service and in-service teacher programs must be re-assessed and reinforced to improve specific programs that pave the way towards inclusion. There is a need for instant policy change; without this change there could be many hurdles in the path of taking the inclusion agenda forward. The government must include classroom teachers in all phases of inclusive policy development.

Modification is the key to successful inclusion

For students with disabilities, the key to success in the classroom lies in having appropriate adaptations, accommodations, and modifications made to the mode of instruction and other classroom activities. Different instructional strategies need to be adopted and modified to cater to the needs of the learners with disabilities.

- Development of individualized instruction plans: There is a need to put into practice a variety of individualized instructional methods in order to cater to children with special educational needs. An individualized instructional plan is a modified plan where a child with a disability is provided with a modified version of the content and classroom activities to develop a better understanding of a particular topic. This involves the contribution of different stakeholders, including teachers and leaders, to develop a plan that can present topics to students with disability in a simplified form.
- Provision of the least restrictive environment: When children with special educational needs study in the same classroom setup with children without disabilities, the school can create a conducive learning environment by modifying the content and strategies according to the type and intensity of disability; this is an example of providing the least restrictive environment. The schools should give an assurance to parents and children that the least restrictive environment will be provided.

The conclusion drawn from our research study is that regular schools can turn into inclusive schools if all individuals in the educational sector work together. It is a complicated process which demands deliberate targeted effort, encouragement, and specific behaviors of leading stakeholders. Pertinent attention should be given to the professional development of teachers in order to enhance their self-efficacy. Suggestions from our study, as well as from earlier related studies, specify the prerequisite to measure teacher attitudes, apprehensions and obligations in their opinions towards professional development in inclusion. The challenge for policymakers will be to address these issues effectively if inclusion for all learners is to become a reality. Inclusive educational practices require continuous support and encouragement for all stakeholders, as inclusion is an endless journey towards a common vision.

REFERENCES

Abbas, F., Zafar, A., & Naz, T. (2016). Footstep towards inclusive education. *Journal of Education and Practice, 7*(10). ISSN 2222-1735

Bandura, A. (1977). Self-efficacy: Toward a unifying theory of behavioral change. *Psychological Review, 84*(2), 191-215. https://doi.org/10.1037/0033-295X.84.2.191 PMid:847061 PMCid:PMC4010856

Dalanon, J., & Matsuka, Y. (2017). Filipino teachers' sense of efficacy in inclusion classes. *Asia Pacific Journal of Research, 58*(1). ISSN 2347-4793

Ghosh, N. (2022). CBR practice and inclusion: Persons with disabilities in North East India. *Disability, CBR & Inclusive Development, 32*(4),114-133. https://doi.org/10.47985/dcidj.516

Hameed, A., & Manzoor, A. (2019). Similar agenda, diverse strategies: A review of inclusive education reforms in the Subcontinent. *Bulletin of Education and Research, 41*(2), 53-66. https://doi.org/10.33015/dominican.edu/2018.EDU.ST.01

Hamenoo ES, Dayan V (2021). Inclusive education and disabilities: Narratives from Ghana. Disability, CBR & Inclusive Development, 32(1). 37-51. https://doi.org/10.47985/dcidj.385

Individuals with Disabilities Education Act (IDEA) Amendments of 1997, P.L. 105-117, 20 U.S.C.

Khan, I. K., Behlol, M. G. (2014). Inclusive education at primary level: Reality or phantasm. *Journal of Education and Educational Development, 1*(1). https://doi.org/10.22555/joeed.v1i1.14

Ozokcu, O. (2018). The relationship between teacher attitude and self-efficacy for inclusive practices in Turkey. *Journal of Education and Training Studies, 3*(6). ISSN 2324-805X https://doi.org/10.11114/jets.v6i3.3034

Raath, S., & Hay, A. (2016). Self-efficacy: A South African case study on teachers' commitment to integrate climate change resilience into their teaching practices. *Cogent education,* 3. https://doi.org/10.1080/2331186X.2016.1264698

Sharma, U., Simi, J., & Forlin, C. (2015). Preparedness of pre-service teachers for inclusive education in the Solomon Islands. *Australian Journal of Teacher Education, 40*(5). Retrieved from http://ro.ecu.edu.au/ajte/vol40/iss5/6 https://doi.org/10.14221/ajte.2015v40n5.6

Shaukat, S., & Rasheed, K. (2015). Student teachers' attitudes towards inclusion in Pakistan. *Bahria Journal of Professional Psychology, 14*(1), 72-89. Retrieved on 13-05-17 from http://oaji.net/articles/2017/6066-1522726888.pdf

United Nations (2015). Transforming Our World: The 2030 Agenda for Sustainable Development. New York: UN Publishing.

Mahwish Kamran[1*], Martin Thomas[2]

1. Iqra University, Pakistan
2. Forman Christian College (a Chartered University), Pakistan

---

[*] **Corresponding Author:** Mahwish Kamran, Researcher in Inclusive Education, Iqra University, Pakistan. Email:Mahwishkamrankhan@gmail.com

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.

www.dcidj.org

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