



DISABILITY, CBR & INCLUSIVE DEVELOPMENT

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Editorial

About generals and too few soldiers...

The past period was for me a time of traveling – real-life and virtual – to different parts of the world. In part, this was needed because I was asked to give presentations at various fora.

I always have been very critical about attending conferences. The last decade especially, I increasingly became critical of the – often – very high costs of organising and attending conferences. That opinion has not changed much in spite of all the advantages and reasons usually given by people who frequently attend conferences. While there is certainly justification for organising such fora, I still have an uncomfortable feeling that the benefits not always outweigh the costs. What is truly new that is being presented in the field of disability and development? Of course, I am aware of all the counter arguments this claim; these vary from the importance of being updated about new developments and best practices, to ‘merely’ the value of networking – and meeting colleagues and old friends – albeit being of importance and for many, likely the most important reason to attend conferences. However, many of the conferences that I visited during my almost 40 years of work in the disability and development field were financed with public funds meant to improve the lives of people with disabilities and their families. Are the high costs of especially global and continental conferences truly justified, and does this benefit those whom we should serve? I don’t have answers, but I remain critical. And I realise when looking at the number of times that I attended or presented papers at conferences that I should of course not criticise anyone else.

I imagine that you as reader wonder what the above critical text about conferences has to do with the title of this editorial. Let me explain this. My most recent assignment took place in Gondar, a well-known historical town in the northwest of Ethiopia in an area close to Tigray. For many of you, the bells may start ringing. Tigray has been an area of intense conflict and human right abuses for the past 2 years or so. An internal war that hardly reaches the attention of mainstream media anymore because there are other wars and conflicts that seem to be more of an interest to report on. For instance, the war in Ukraine, which has a geopolitical impact that is at times hard to realise. However, we know that in wars, it is generally not the generals who die or get wounded on the battlefield, but it is the

soldiers sent to the battlefield, sometimes even unprepared, poorly trained and not well equipped.

Now, I am not writing about (internal) wars or conflict and its resulting immense human suffering, also in terms of those who become disabled: civilians as well as combatants on both sides of conflict.

I was recently invited by the Committee on Victim Assistance of the *Convention on the Prohibition of the Use, Stockpiling, Production and Transfer of Anti-personnel Mines and on Their Destruction* to speak about the importance of CBR for persons who suffer from physical or psychological injury, economic loss, social marginalisation or substantial impairment of the realisation of their rights caused by the use of cluster munitions. At this Victim Assistance Experts Meeting, the testimonies were touching and encouraging. At the same time the tragedy continues. Mankind (and thus countries) still – after adopting a 25- year-old Convention, produce and use Anti-personnel Mines and the suffering and casualties caused by anti-personnel mines, is astonishing.

Coming back to the general and soldiers, I am of the opinion that there are other ‘wars’ happening too. One of my African colleagues – a co-trainer during the one-week training at the University of Gondar on handling cerebral palsy within CBR – triggered me to think this. When reviewing the status of CBR and doing some fieldwork in Gondar town, he stressed that in CBR in general – so not at Gondar specifically – we have too many generals and too few soldiers. What he meant is that in most cases, CBR field staff is poorly trained; work under miserable conditions; are the least paid; are the least recognised and valued, and hardly have the instruments and means to be successful while they are expected to be at the core of CBR programmes. I would even argue that field staff are and will be for the coming decades the most vital part of rehabilitation systems! There are however, in general, too few of such vitally important people and usually they are even not formally part of the system but get a meagre stipend. These people are the soldiers, but they have not the equipment to win the battle. They often become demoralised as the needs that they observe are too big to handle.

At the same time, the generals (therapists, managers, policymakers) sit in their nice offices and hardly visit the (battle)field, the community. They are involved in STARS¹ exercises in order to get themselves more stars and more colleagues of

1 A Tool for the Systematic Assessment of Rehabilitation Situation

which many have absconded the battlefield to move to greener pastures where (financial and academic) reward is many times higher than in their own country. At best, they write their reports, publications, and often develop new strategies without hardly practical experience in fieldwork themselves or even knowing, from evidence, whether that old strategy ever had an effect in the first place.

It appears at times that the CBR battle has been lost. In fact, it is the community and within the communities that many adults and children with disabilities, as well as their parents and families, are on the losing end. What is your view on this? Should we continue writing our reports, publications and develop new strategies? Should I continue to produce an editorial that won't be taken too seriously?

This is the story CBR, a story of the generals and the soldiers. I hope that you ask yourself whether you are a general or a soldier and, if you are a general, that you ask yourself in how far you are supporting the soldiers! The reality is that we keep marching on with ever decreasing numbers of soldiers!

Your editor-in-chief.

Huib Cornielje

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Emotions, Relationships and Behaviour: a Qualitative Study on Experiences of Stigma among Persons Affected by Leprosy in Northern Nigeria

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ABSTRACT

Purpose: *Leprosy is a highly stigmatised disease with far-reaching psychosocial and economic consequences. This study explored the social consequences of leprosy and the factors that drive stigma among persons affected by leprosy in northern Nigeria.*

Method: *The study used a cross-sectional design with a qualitative approach. Semi-structured in-depth interviews were conducted with 20 persons affected by leprosy. Data were collected from September to November 2020. ILEP's four stigma domains (emotions, thoughts, behaviour and relationships) were used to develop the interview guide and to analyse the data. The framework approach to thematic analysis was performed.*

Results: *The study identified: (1) negative societal attitudes and behaviour towards persons affected by leprosy, (2) restrictions in social participation among affected persons, such as in communal eating, job opportunities and education, (3) negative impact of leprosy on marital life and marriage prospects, also experienced by family members, and (4) negative emotions such as sadness and despair. Some of the problems seemed to be caused by negative perceptions and a lack of knowledge of leprosy. The main coping strategies included adjustments in behaviour (e.g., marrying other persons affected by leprosy and communal*

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eating amongst persons affected), and religion (by seeking consolation through faith in God/Allah).

Conclusion: *High levels of stigma were experienced by the participants. This underscores the importance of sustained information, education and communication interventions via traditional and modern media, to fill knowledge gaps and address misconceptions and myths about leprosy.*

Key words: *stigma, leprosy, participation, Nigeria*

INTRODUCTION

Leprosy, one of the oldest recorded diseases, is caused by *Mycobacterium leprae*. The disease affects the largest and the most visible organ of the body, namely the skin (Attama et al., 2015). It is an infectious disease that can have far-reaching psychosocial and economic consequences (Rao, 2015). Leprosy can cause physical impairments and is a highly stigmatised disease.

Stigma is “a social process, experienced or anticipated, characterised by exclusion, rejection, blame or devaluation that results from experience, perception or reasonable anticipation of an adverse social judgment about a person or group” (Weiss et al., 2006). It enables varieties of discrimination that ultimately deny an individual or group full social acceptance, reducing opportunities (Goffman, 1963) and fuelling social inequalities (Parker & Aggleton, 2003). Stigma also influences population health outcomes by worsening, undermining, or impeding several processes, including social relationships, resource availability, stress, and psychological and behavioural responses (Hatzenbuehler et al., 2013). Despite enormous cultural diversity, the areas of life affected by stigma are remarkably similar across different stigmatised conditions. They include mobility, interpersonal relationships, marriage, employment, leisure activities, and attendance at social and religious gatherings (van Brakel, 2006; Rao, 2010; van Brakel et al., 2019).

Leprosy-related stigma can persist even after release from treatment and remains an enduring challenge to leprosy control programmes (Weiss et al., 2006; Udo et al., 2013). It can impact the emotions, thoughts, behaviour, and relationships of persons affected (The International Federation of Anti-Leprosy Associations - ILEP, 2011). For example, persons affected by leprosy experience restrictions in education, employment, and participation in social events (van Brakel, 2006). In a study in India, persons affected were found to have left their families, including

their spouses and children, fearing the repercussions of their condition (Kaur & van Brakel, 2002). A diagnostic label of leprosy may alter the social identity of the individual and the family. When a person is diagnosed with leprosy, sometimes the social status of the entire family is reduced, and all the family members may be considered inferior by their community.

Leprosy-related impairments have often been associated with stigma. For example, a study in Nepal showed that persons affected by leprosy still experience negative behaviour and that 95% of the persons that experienced social stigma had visible wounds, swellings, and deformity of the feet and hands (de Stigter et al., 2000). Another study, in India, found that the proportion of families of persons affected with deformities that faced problems was nearly ten times higher (57%) than those without deformities (6%) (Kopparty et al., 1995). In addition to external manifestations of the disease, leprosy-related stigma has also been attributed to cultural and religious beliefs, fear of transmission, and the association of the disease with people who are considered inferior (van Brakel, 2003; Sermrittirong & van Brakel, 2014).

Despite leprosy being declared eliminated as a public health problem globally, over two decades ago, it remains a problem in Nigeria. Northern Nigeria reports more new cases of leprosy compared to the South (Mustapha et al., 2012). Studies have also reported a high level of stigma across Nigeria (Ebenso et al., 2019; Ogban et al., 2020). Addressing stigma in northern Nigeria requires an understanding of the degree of stigmatisation and the underlying mechanisms that fuel leprosy-related stigma. This could inform the development of culturally sensitive stigma-reduction interventions.

Objective

This study explored the social consequences of leprosy and the factors that drive stigma among persons treated for leprosy in the context of northern Nigeria, from the perspectives of the persons affected.

METHOD

Study Design

The study used a cross-sectional design with a qualitative approach. It was the qualitative component of a mixed methods study that focused on the prevalence

and determinants of social participation restriction among persons affected by leprosy, who were released from MDT at least two years previously. Semi-structured in-depth interviews were conducted with persons affected by leprosy.

Study Site

The study was conducted in Kano State, Nigeria. The state recorded 118 new cases out of Nigeria's 2,424 new cases in 2020 (The Nation News Paper, 20th June, 2021). In-depth interviews were carried out in both urban and rural catchment communities of Yadakunya Leprosy hospital, which is a major leprosy rehabilitation centre located in northern Nigeria. This 153-bed hospital houses a leprosy clinic administering multidrug therapy (MDT) to people diagnosed with leprosy. The hospital also takes care of leprosy complications, and offers orthopaedic services, general outpatient services, antenatal care, and other maternal health services.

Study Sample

The participants were selected by stratified purposive sub-sampling from the quantitative strand sample until data saturation was reached. Potential participants were stratified by sex (male and female), marital status (married, divorced, widowed), residence (rural and urban), and educational level (at least primary education versus no formal education) to ensure representation and maximum variation in experiences.

Inclusion criteria:

Persons affected by leprosy, 18 years of age or older, who used to receive MDT at the clinic and were discharged from treatment at least two years prior to the study.

Twenty persons were found eligible for inclusion in the study.

Theoretical Framework of Stigma and its Impact

The elements of the International Federation of Anti-Leprosy Associations (ILEP) Stigma Framework were used, which identified emotions, thoughts, behaviour, and relationships as the four stigma domains that have impacts on persons affected by leprosy. The domains are said to be interconnected and are manifested in different degrees, moments, and contexts (ILEP, 2011). The feelings of "fear, grief, depression, guilt, shame, anxiety, low self-esteem, anger, inability to express such

feeling and hopelessness” constitute the first domain. Negative and pessimistic thoughts about self, the world, and the future are part of the second domain. Emotions and thoughts that are in the first and second domains determine the way affected persons react to the health condition, and subsequently influence their behaviour. This is manifested through loss of confidence, avoidance, isolation, and withdrawal from social life. This (behaviour) is the third domain. The fourth and final domain is relationships, and is described as “rejection, forced isolation, and restricted social participation” (ILEP, 2011).

Data Collection

Data were collected from September to November 2020. The in-depth interviews were conducted by an experienced social scientist, using the interview guide. The questions in the interview guide were formulated to gain insights into anticipated and experienced stigma and the associated drivers. The interview guide was based on the results of a quantitative survey that was conducted prior to this study. The face-to-face interviews were conducted in the catchment communities, while ensuring privacy and observing COVID-19 precautions. Themes in the interview guide included: response to diagnosis, disclosure, attitudes of others (thoughts on leprosy, general attitude of the community of persons not affected, experiences with education, work, marriage, participation in social events, differential experience of persons who have visible impairments), and preferred occupation.

Data Analysis

The interviews were audiotaped, transcribed verbatim, and translated from the local Hausa to the English language. Subsequently, the anonymised transcripts were coded and analysed manually. The framework approach to thematic analysis was performed (Pope et al., 2000) and included familiarisation through repeated reading, coding, theme generation (a priori from the interview guide and emergent from the data), applying the codes to the transcripts, matrix formation, deductive content analysis, and interpretation.

Ethical Approval

The study was approved by the Kano State Research Ethics Committee of the Ministry of Health vide a letter number MOH/OFF/797/T.1/2068, dated 31st August 2020. All the participants were informed about the objectives of the

study, voluntary participation, the risks and benefits of participating, their right to withdraw at any point in time, and the confidentiality of the data. Written informed consent was obtained from all the participants prior to data collection.

RESULTS

A total of 20 persons affected by leprosy were interviewed in depth. The average age of the participants was 52 years, with ages ranging from 38 to 72 years. Ten participants were male, and 10 were from rural areas. While 4 participants had completed at least primary education, the rest had no formal education. The majority of the participants ($n=14$) were married, and six of them ($n=6$) had no current partner. Six male participants had multiple spouses. Eleven participants were petty traders, four were beggars, three were farmers, one was a road transport union worker and one was a civil servant (see Table 1). All the participants were Muslims (see Table 1 below).

Table 1: Demographic Attributes of Persons affected by Leprosy who participated in the in-depth Interview in Kano, Nigeria (n=20)

Characteristics	Category	Frequency
Age (years)	30-39	2
	40-49	4
	50-59	10
	= or >60	4
Total participants		20
Male	Rural	5
	Urban	5
Female	Rural	5
	Urban	5
Total participants		20
Marital status	Married	14
	No current partner (single, widow, divorced)	6
Total participants		20
Level of education	No formal education	16
	Formal education of at least primary school level	4
Total participants		20
Occupation	Beggars	4
	Manual workers including farming	4
	Petty trading,	11
	Civil servant	1

Religion	Islam	20
	Other faiths	0
Total participants		20

The in-depth interviews yielded six major thematic areas. These included: response to leprosy diagnosis, disclosure of diagnosis, community attitudes and behaviour, intermarriages, preferred occupation, and participation in social events.

Response to Leprosy Diagnosis

In their reaction to leprosy diagnosis, participants revealed social prejudice against leprosy, myths about the disease, and lack of knowledge about transmission. In addition, the diagnosis of leprosy uniformly evoked negative emotions such as sadness, anger, and despair. Participants indicated that their family members and significant others also experienced negative emotions.

“I was not happy at all. My mother also cried a lot when she discovered I had leprosy. But there was a time I got burned in an open fire unknowingly. When I showed my uncle, he shook his head, felt bad, and said “this is leprosy” (61-year-old male).

Negative reactions were caused by society’s perception of leprosy as invariably leading to deformities, stigma, and social exclusion. These apprehensions fuelled fear and negative emotions among newly-diagnosed persons and their families.

“Those that were infected have lost their fingers and other parts of their body. People run away from them, pointing fingers saying that they are infected with leprosy; also, I considered how people with this disease are treated in the society” (60-year-old male).

Other concerns were the eventual loss of friends and marital dissolution. Some married women affected by leprosy requested divorce as they could no longer cope with the demands of marital life and the embarrassment of co-wives. While none of the men reported that they feared being unable to live up to the demands of marital life, some men said they were abandoned by their wives because the wives believed that men afflicted with leprosy could no longer provide for the family.

“My two wives abandoned me because of this condition. They said I could not take care of them. So, someone whose wives deserted him, and ran away from him, is there any more obstacle to face than that?” (65-year-old male).

One participant said that she was forced to abandon her hometown and migrate in order to escape the shame and ridicule associated with leprosy.

“I felt bad, that was the reason I left my hometown [migrated] to this place where I remarried and had my children as people were calling me names in my hometown and I felt really bad” (52-year-old female).

Others said they were mentally disturbed by community members; this affected their mental well-being, but they held on to their marriages and sought treatment outside their communities.

Post-diagnosis, participants with visible impairments described experiencing a negative life transformation due to the stigma and social isolation.

“Because I witnessed a change in my life, I could no longer do things I took for granted. For instance, my hands were bleeding in public, and even my close friends no longer extended their hands to shake mine or eat with me. It is a whole new life” (58-year-old male).

Disclosure of Diagnosis

Participants indicated that parents were informed about their disease first, in most cases, especially mothers, then fathers, grandparents, and other family members. This was followed by friends and other close confidants. A few participants consulted healthcare professionals in search of a diagnosis and treatment. In general, disclosure was met with negative emotions ranging from sadness to anger.

‘My mother was the first to know. She was very angry and at that time I didn’t know exactly what her anger was about, nor did I know the danger of this infection [leprosy]’ (53-year-old female).

Family members were worried about where to get effective treatment. Parents, especially the mothers, became preoccupied with the search for a cure. The actions taken by participants were largely dependent on the health-seeking behaviour of the family. Traditional medicine was often the first option, based on firm traditional and cultural beliefs.

“My mother continued searching for medication to get me healed. There was no rest of mind as the focus was on how to get a cure. Wherever she thought or heard of a place that treated such cases, she ran to that place for help. She continued like this into my

adulthood, and I also started looking for medicine myself. Because of this experience, if I meet a person newly infected with leprosy I can heal him completely using traditional medicine” (60-year-old male).

Some participants indicated that in general the attitude of family members did not change towards them, and they also felt it was their destiny. Indeed, the majority of participants and the people they spoke to had strong belief in fate and destiny. Friends consoled the affected persons saying it was their fate as destined by God/Allah. This sense of spirituality provided succour and hope, leading to acceptance of the situation.

“I first told my elder sister and she counselled me and asked me to be patient and that God is with us and it is my fate, and I should consider it a trial from God in good faith. She was not happy and every time we met, her words were remain patient and live with people well, whatever stigma you encounter, and do not worry because this is from God” (52-year-old female).

Some participants faced strong opposition from their parents regarding hospital treatment, out of fear that doctors would amputate body parts. Some had to wait till the opposing parent’s demise before they could access hospital treatment, or they sneaked into the hospitals secretly, without approval from their parents.

In addition, a participant described experiences of enacted stigma in the form of discriminatory experiences at a close relative’s home. Narrating her ordeal, a woman described as unforgettable the denial of permission to stay and receive treatment at her uncle’s place.

“Some people sympathised with me. It was when I came here [uncle’s house] that the infection worsened. I left my husband and came here to live with my uncle. However, I discovered some changes in attitude from his family members. I told him that I will live here [in his house] and be going to collect my medicine. He then told me that I could not stay with him because the disease is transmissible. I was shocked. If my maternal uncle disowns me, where else can I go? This, I cannot forget” (47-year-old female).

Community Attitudes and Behaviour

While some participants reported no untoward social responses from the community members who continued to invite them to social functions, others described various forms of stigma and social exclusion, such as avoidance, social distancing, and refusal to engage in communal eating.

“Yes, it is basic you will see changes from some individuals in the community. Like some people when you go to the mosque, market, and other places, you will notice they would not like to come close to you. Similarly, when you attend marriage ceremonies and food is served, some people will not eat with you. But some other people will eat with you” (61-year-old male).

There was evidence of anticipated stigma before and after diagnosis, and enacted stigma after diagnosis of leprosy. Negative perceptions about leprosy informed anticipated stigma, while lack of understanding of the infectiousness and mode of transmission heightened the fear of acquiring infection, thereby fuelling stigma and social exclusion of persons affected. Some participants also blamed poor hygiene practices of some affected persons as being partly responsible for the persistence of stigma from community members.

A participant reported migrating from her hometown because of the shame of having leprosy. The use of traditional medications was popular. Treatment completion which renders affected persons non-infectious did not eliminate stigma. The persistence of stigma was worse among those with visible impairment.

“There is much difference in the way community members treat those with visible impairments. They fare worse. I remember someone that refused to shake hands with a leprosy-affected person with visible impairments. He instead used a stick that he held at one end and gave the leprosy-affected person the other end to replace a direct handshake” (51-year-old male).

Beyond the family, a participant reported that his neighbour ordered the cutting down of a tree to prevent affected persons from gathering under it. Similarly, items (such as a wooden bench) borrowed by persons affected were washed thoroughly by the owner before use. Stigma also manifested in educational institutions, both formal and non-formal (Qur’anic) schools. Other (unaffected) students avoid students affected by leprosy and sometimes leave the class to avoid sharing seats. A participant who was a student, shared his experience in a non-formal school where, despite being the major contributor to food, his friends barred him from eating with them.

“An event happened when I was in Arabic school in [location] that I won’t forget. ... [my friends] decided to stop eating with me because of my condition. This was revealed when one day we warmed leftover food and when I attempted putting my hand in the bowl to start eating, one of my friends confronted me and said ‘honestly [name] you are cheating us’. At that time, I felt bad, and from then on I had to eat alone. That was despite me being the largest contributor of [food] that we ate” (61-year-old male).

In addition, commercial vehicles avoid carrying persons affected with visible impairment, even if there are vacant seats.

“The second unforgettable incident happened at [location] within old Kano city when I waved down a commercial bus and when the driver and conductor realised that I had an impairment, they zoomed off and refused to take me” (61-year-old male).

Participants indicated that they were eager to go to school and study, but that stigma towards them constituted a barrier. Some participants believed that affected persons had limited opportunities compared to their unaffected counterparts. However, enacted stigma towards affected persons by non-affected classmates results in minimal interaction between affected and unaffected persons. Some participants said that persons with disabilities not caused by leprosy have better educational opportunities as compared to persons affected by leprosy, because of negative perceptions and a lack of knowledge of leprosy. Persons affected by leprosy and also their children face stigma mainly from other students in educational institutions.

“Educational opportunities were limited for leprosy clients. There is stigmatisation which is very usual. We want to learn but interaction with unaffected people is difficult, and it is not easy to sit together at the same time in the same place to learn. If you look at this situation, there is room for crippled or deformed people to study; likewise the blind men are all recognised in the community, and they can interact with people well without showing any differences, but for people suffering from leprosy, their case is different and it is only God that loves us” (40-year-old female).

Participants also lamented the difficulty in getting accommodation whenever they travelled. They are denied hotel accommodation when the hoteliers discover that they are affected by leprosy, even if they can afford their stay. In addition, apart from maintaining a social distance, some relatives and community members stigmatise them by rejecting their food and drinks. This is not the case within the community of affected persons.

“Affected persons face stigmatisation from unaffected persons. They will not sit near you; they will not drink from you or eat your food and when you visit them, they treat you differently. When you want to drink, they will not provide you with a clean container because you are a sick person. Even your relatives stigmatise you and behave towards you differently. However, within our community of affected people, we don’t have a problem and we do everything together. But members of a neighbouring village stigmatise us and call our children all sorts of names. Our children have to attend separate schools because

of stigmatisation against their parents”

(52-year-old female).

Intermarriages

Another challenge relates to marriage proposals. These are promptly turned down, especially by parents and relatives of the girls, as soon as they discover that the man has leprosy.

While intermarriages did occur, they were often mainly between a man affected by leprosy and an unaffected woman. Even then, these marriages were carried out before the man was diagnosed with leprosy. These intermarriages faced societal opposition.

A participant described a boycott of a wedding ceremony by neighbours in protest against marriage between affected and unaffected persons. To avoid such challenges, persons affected, as a group, resolved to marry among themselves:

“There was an episode where one of us married an unaffected woman with her consent and that of her parents. But the neighbours boycotted the wedding wondering how she could accept marrying a leprosy-affected man. Therefore, to avoid problems, we have resolved to marry among ourselves (58-year-old male).

According to the participants, community opposition and the opposition of parents of the prospective bride and groom, if one of them is leprosy-affected, are common. This opposition is strongest if the girl is not leprosy-affected but the man is. This often ends in the dissolution of the agreement to go ahead with the marriage. The participants explained that intermarriages between affected and unaffected persons were reported to be more common in other parts of Nigeria, but were rare in the north.

“I married my husband in my village. He was also affected with leprosy. Some people do marry unaffected people. For instance, when I went to Lagos, I discovered that most of their wives are unaffected women. But here [in the North], it is a rare phenomenon for a person affected by leprosy to marry an unaffected person” (40-year-old female).

As mentioned previously, apart from restricting potential partners to affected persons, divorce seemed common following leprosy diagnosis, mostly at the request of women.

Disappointments regarding marriage proposals were not limited to periods of

treatment; it persisted after being declared cured, as the public still considered them active leprosy clients.

“Yes, we encounter rejection regarding intermarriages with unaffected persons. I proposed to marry several unaffected women after I was declared cured, but they all refused because they still considered me a leprosy client even after cure” (51-year-old male).

Challenges with family formation were experienced by both men and women. Divorce as a result of leprosy was common. Often, the stigma was extended to children of persons affected by leprosy, who also faced challenges in their marriage.

“Yes, what I experienced was when I got married to my first husband, people started complaining to him and asking why he married a person affected by leprosy. I had to leave my matrimonial home to my family house after which I was brought here to Bela to receive medical attention. My parents later requested him to divorce me. After my divorce, I then remarried a person affected by leprosy. Secondly, one of my daughters got married to an unaffected person but because we [her parents] have leprosy, the marriage ended. Her husband’s family members sent her away. We now prefer giving out our daughters to our people [persons affected] because of these experiences” (52-year-old female).

In sum, leprosy affects marriage prospects and can be a reason for divorce, resulting in persons affected marrying other persons affected.

Preferred Occupation

In compliance with healthcare workers’ counsel, persons affected by leprosy selected their jobs carefully. They engaged in petty trading and selling inedible essentials such as firewood and kerosene, either directly or through their children. They avoided physically demanding jobs and selling cooked or ready-to-eat food items because the public perceived that for any item touched by an affected person to be safe for consumption, it needs to be cooked after purchase.

“No one will buy cooked food or ready-to-eat food from you because they feel you have contaminated it. They prefer that anything you touch should be cooked to kill any germs from you before use” (58-year-old female).

According to the study participants, despite the careful selection of occupation, the chances of making good sales and profit, given a particular capital and market location, was lower for persons affected compared to their unaffected peers.

“You know, because of peoples’ stigma and negative perceptions, with this kind of infection you cannot cook and sell, so preferably you can sell firewood, kerosene, vegetables like tomatoes, pepper and palm oil. Even for the inedible items, if the public knows that you are a leprosy-affected person, they will not buy from you. But what we do is if you have a small boy, he can sell it for you. But for me, I can do everything but the impaired ones they cannot do that” (55-year-old female).

Participants confirmed that begging was common among persons affected by leprosy. They identified lack of education, unemployment, and lack of capital as reasons for begging. Some participants attributed it to the belief in ancient times that persons affected by leprosy could seek divine healing by humbling themselves through begging. Others reported that persons affected had turned begging into a business by engaging their children as fronts, while others beg because they lack formal education and cannot be employed in the formal sector.

Participation in Social Events

Some participants told us that they attend social gatherings of relatives, friends, and neighbours affected and unaffected by leprosy, with little or no experience of stigma.

“Yes, I participate in every activity. I have not experienced any stigmatisation from the unaffected people. We do everything together. I get invited to ceremonies like every other person. If there is ‘Ashobi’ [uniform cloth made specifically for a ceremony], they send the sample to me and I make mine” (40-year-old female).

However, some participants indicated that they gradually withdrew from social engagements. Others mentioned that some persons affected by leprosy limited themselves to social events organised by their relatives and close family members. Participants again emphasised that persons with visible impairments fare worse than their counterparts without impairments. They avoided other invitations based on previous unpleasant experiences, including various forms of stigma from other invitees.

“Sometimes if you intend to go to such public events and you remember your condition and previous encounters, you change your mind. Others do not even try to go to public places because they know what they will face, so they prefer to stay back. Whatever you do to your body, they will still avoid you. Those that were declared cured also do not fully participate in public events” (53-year-old female).

Participants' experiences of communal eating at such social events were varied. Those with visible impairments especially, experienced more restrictions during communal eating. Some participants restricted group eating to their relatives and other persons affected, out of fear of discrimination. While some affected persons engaged in communal eating during ceremonies, just as they used to before being diagnosed, albeit using a spoon (eating with hands is normal in this part of Nigeria), others avoided eating with unaffected people due to anticipated stigma. However, eating with other affected persons was acceptable.

"No, to be honest, I don't eat with other people because of this infection. It is better to eat alone or among yourselves. They will not eat food with you; it is only those among you with the same condition that will eat from and with you. We don't eat together; even when you attempt to eat, some will refuse to eat with you. So it is better not to attempt it" (50-year-old female).

During ceremonies, while some persons affected by leprosy ate communally, using a spoon as instructed by health professionals, most of them avoided eating in public. They preferred to eat with their members or opt for 'take away' packs to avoid embarrassment.

"No, I don't eat with other people. I would rather ask them to bring my own, with a spoon to eat separately, because nobody will eat our leftovers except dogs" (65-year-old male).

When asked if there were changes in leprosy-associated stigma over the years, one participant was of the view that there has been some reduction, attributing it to increased public awareness and healthcare workers treating persons affected by leprosy with respect.

DISCUSSION

The study explored the experiences of stigma among persons affected by leprosy in northern Nigeria. The findings transcend the four domains of the impact of stigma in the ILEP Stigma Framework (ILEP, 2011). These include: (1) negative attitudes and societal behaviour which seem to be caused by negative perceptions and lack of knowledge of leprosy, (2) restrictions in social participation such as in communal eating, job opportunities and education, (3) the negative impact on marital life and marriage prospects also experienced by family members, and (4) the negative emotions this causes.

Attitudes and Behaviour of the Community

Themes indicated pervading myths and incorrect fears about leprosy due to its perceived infectiousness and the resultant disabilities. These could be fuelled by unfounded and unscientific views about the infectiousness of the disease and the fear of dealing with affected persons. The findings are similar to reports in India and Nepal where persons affected by leprosy have been subjected to all sorts of isolation and forced migration (Try, 2006; Poestges, 2011).

Participation Restrictions

The extension of stigma to family members has also been reported in other studies in Nigeria (Ebenso et al., 2019), Cameroon (Nsagha et al., 2011), Ethiopia (van't Noordende et al., 2020), Nepal (Marahatta et al., 2018) and India (Frist, 2000). If a family member is affected by leprosy, it seems that it alters both the individual and family's social identity, with damaging consequences. This could include social isolation, avoidance, rejection, and diminished marital prospects. Apart from lack of knowledge regarding leprosy, this is probably accentuated by considering leprosy as divine punishment for past sins (Lewis, 1987) and some religious scriptures cautioning against matrimonial alliances with families of persons affected by leprosy (Brody, 1974; Fordham University, 1998). This highlights the need to engage religious and community leaders, and healthcare workers, to dispel myths and clarify the mode of transmission, availability of treatment, and rehabilitation of persons affected as a means to minimise stigma and discourage the use of traditional medications. It is also necessary to empower organisations of persons affected by leprosy to be actively involved in stigma-reduction interventions.

Social participation restrictions related to communal eating, experienced by persons affected, has been reported in parts of Nigeria (Ogbewe, 1999; Ebenso, 2007) and Brazil (Lesshafft, 2010). Underlying this could be the fear of acquiring leprosy, resulting from poor knowledge about transmission. Most community members view persons affected as infectious even after release from treatment. This could result in public avoidance and non-invitation of affected persons to social events. This underscores the importance of sustained information, education and communication interventions via traditional and modern media to fill knowledge gaps, and address misconceptions and myths about leprosy.

The negative experiences of affected persons and their children in educational institutions limits educational opportunities as earlier reported in other studies in

Nigeria (Ebenso & Ayuba, 2010), South Sudan (Luka, 2010) and Indonesia (Lusli et al., 2015). The low educational attainment and stigma limit job opportunities to occupations deemed by society as 'appropriate' for persons affected. This restricts the economic participation of persons affected to subsistence agriculture, animal husbandry, petty trading, or begging, thereby perpetuating the cycle of poverty in affected families (Kaur & van Brakel, 2002). These are important considerations for holistic educational, occupational and socioeconomic rehabilitation of persons affected and their families.

Thoughts and Emotions

Participants in this study felt bad, sad and expressed a sense of despair in response to the diagnosis of leprosy, consistent with the first domain of the ILEP Stigma Framework (ILEP, 2011). Previous studies in Nigeria (Ubah, 1992) and Indonesia (Peters et al., 2013; Lusli et al., 2015) reported that such a diagnostic label evoked strong negative emotions, probably fuelled by society's image of leprosy as invariably leading to deformities, stigma, and restricted social participation. These negative emotions were not restricted to persons affected by the disease, but also involved family members. It was, however, tempered by a strong sense of spirituality facilitating acceptance of the disease as their fate and an inescapable destiny. This concurs with findings from Brazil, where spirituality/faith was also a source of strength for persons affected (van't Noordende et al., 2021). This is important as it could minimise denial by serving as a coping strategy for religious people.

Impact on Marital Life

In the present study, the thought of living with disabilities and its consequences made participants worry about their future. They contemplated life with leprosy and the consequences on their relationships and marriage. For instance, some married women were particularly concerned about how to cope with co-wives. Some of them requested a divorce at the thought of living with co-wives. Others deserted their matrimonial homes and settled elsewhere to avoid being stigmatised in their original communities or by co-wives. These pessimistic thoughts about self, the world, and the future are part of the second domain of the ILEP Stigma Framework (ILEP, 2011) and are similar to reports from India and Nepal (Try, 2006; Poestges, 2011). Apart from marital instability, separation, or divorce, leprosy also diminished future marital prospects for persons affected

and their families. Contrary to the general belief that women are more affected in terms of marriage prospects than men (Rao et al.,1996; Le Grand, 1997; Try, 2006), in the present study participants indicated that marriage proposals were promptly turned down, especially by parents and relatives of the women, as soon as they discovered that the man has leprosy. This treatment was also meted out to family members to a certain degree. Underlying this is the desire to protect the family identity and protect the lineage from an 'inheritable' disease (Stangl et al., 2019). Community enlightenment programmes are required to address the misconceptions that drive this form of stigma.

Behaviour

In line with the impact of the first and second ILEP stigma domains on the behaviour of persons affected (ILEP, 2011), participants reported self-exile and isolation among persons who could not cope with the diagnosis. Some experienced a difficult time, and the majority established new friends among persons affected by leprosy instead of the community they originally hailed from. Some questioned why society treated them that way, because even after being released from treatment that made them non-infectious, society still treated them as being different. Their children faced similar challenges in schools and other public places. Intermarriages between persons affected and non-affected were problematic when they occurred. Even the daughters and sons of persons affected by leprosy are stigmatised and face similar challenges in marriage. These forced persons affected by leprosy to intermarry among themselves or to prefer that their daughters who are not affected marry persons affected by leprosy, to promote peaceful and stigma-free married life. These findings are similar to what was reported in India (Poestges, 2011).The adjustments in behaviour concerning marriage – marrying other persons affected by leprosy instead of 'intermarriage', and communal eating that is done 'amongst themselves' - are coping strategies that are temporary. However, more lasting and sustainable stigma-reduction activities based on socioeconomic rehabilitation programmes are needed in communities in the studied region.

Relationships

The study findings revealed forced migration, rejection, self-isolation, and social participation restrictions. Participants demonstrated perceived or felt stigma, experienced or had enacted stigma, and demonstrated internalised stigma. These

findings are similar to a report from Brazil where it was stated that leprosy-related stigma was more 'persistent than the disease' (Silva et al., 2014).

Perceived stigma was demonstrated by affected persons and their immediate families following the news of being affected by leprosy. Some endured, while some had to leave their communities on self-exile to other communities, usually of persons affected by leprosy, located close to where leprosy treatment could be accessed. The act of migrating from one's original community to another, either on self-exile or by force, has been reported in Nepal where leprosy-diagnosed persons are forced to leave their families to live in isolation around the riverbanks (Poestges, 2011). The respondents in the current study experienced stigmatisation by neighbours, and rejection and isolation from family and community members in several ways. In Brazil, changes were also reported in the family, the receptiveness of neighbours and co-workers, and the social lives of persons affected, after the diagnosis of leprosy (Silva et al., 2014).

Strengths and Limitations of the Study

The strength of this study lies in the fact that it is one of its kind being reported from the study area. Being a qualitative component of a mixed methods study, it provided a more in-depth understanding to the quantitative findings (reported elsewhere). However, its cross-sectional nature limited causal attribution. It however provided information for further research on the subject to be conducted in the study area.

CONCLUSION

The study found profound stigma manifesting as negative attitudes and societal behaviour, restrictions in social participation impacting on marital life and prospects, and limiting jobs to those deemed "appropriate" for persons affected. These resulted in adjustments in behaviour, such as marrying other persons affected by leprosy instead of 'intermarriage', and communal eating 'amongst themselves'. These coping strategies are temporary and need to be replaced with more sustainable stigma-reduction activities in communities, based on socioeconomic rehabilitation programmes in the studied region.

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The data underlying this article will be shared on request to the corresponding author.

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Role of Young Carers of Parents with a Disability in Sierra Leone and Cameroon: an Explorative Study

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ABSTRACT

Purpose: *This study aimed to get insights into the role of children who are caring for their parents with a disability in Sierra Leone and Cameroon.*

Method: *Quantitative and qualitative data were collected using two different questionnaires that were distributed among parents with a disability and community fieldworkers. The parents were asked to answer questions about their personal life and the roles that their children, other family members and aid organisations play in their lives. The fieldworkers were asked about their experiences and opinions regarding children's roles as caregivers for their parents.*

Results: *It was found that children supported their parents in performing domestic chores, childcare, and intimate and general caregiving. They also gave emotional support, mostly by showing compassion. Most parents wanted more help in raising their children, as well as financial support. Fieldworkers judged the caring roles of children as a responsibility, a blessing, or a burden.*

Conclusion: *This study indicates that children play diverse roles in caring for their parents with a disability. Future research could map cultural norms and expectations about a child's caregiving responsibilities, and focus on the possible consequences for a young carer, like dealing with poverty or being unable to attend school.*

Key words: *children, caregiving, low- and middle-income countries, emotional support, poverty*

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INTRODUCTION

Global estimates suggest that around 15% of the world's population lives with some form of disability (World Health Organisation, 2011), with disability being more prevalent in low- and middle-income countries (World Bank, 2021). Disability affects not only the individual, but also the social environment (Parnes et al, 2009). In low- and middle-income countries especially, where poverty limits the access to rehabilitation and health-care facilities (Department For International Development - DFID, 2000; United Nations, 2020), families and communities play an important role in caring for their family or community member with a disability (Elwan, 1999). When parents have a disability, it might be up to their children to take care of them.

According to Skovdal et al (2013), there is an urgent need for clarification regarding when caregiving by young people is or is not appropriate. A young carer is defined as "a person under 18, who provides or intends to provide care for another person. A person is not a young carer if the person provides or intends to provide care (a) under or by virtue of a contract, or (b) as voluntary work" (The National Archives, 2014). Becker (2007) suggests that this definition makes it possible to distinguish between children who are substantially and regularly more involved in caring, who would classify as young carers, and children who are involved in particular aspects of caring which are neither substantial nor regular. The latter do not experience any negative or damaging outcomes of the care they provide, whereas young carers will experience these negative outcomes (Becker, 2007).

The exact impact that caring for a parent has on a child is dependent on the extent of the caregiving, the nature of the caregiving, the time that is involved in caregiving, and the restrictions that this causes for social and educational participation (Becker, 2007). These can include restrictions in educational attainment, restrictions in participation possibilities, and restrictions in general development (Becker, 2007).

Negative outcomes for young carers include more worries and problems concerning their well-being, than for children who do not provide or intend to provide care for another person (Gibson et al, 2019). Another negative outcome is that caregiving work is negatively associated with schooling outcomes for young carers. Less time for schooling activities due to working for a longer period of time can lead to school failures and early school dropouts (Zabaleta, 2011). Whereas

children who are not carers might experience lack of money as the main barrier to fulfilment of their future ambitions, young carers additionally experience the responsibility of caring for their family members and the lack of qualifications due to lack of education (Warren, 2007). It should be acknowledged that for some households the only strategy for survival is to have the child(ren) care for their parents or to have the child(ren) work (Robson, 2004). Young carers are usually caregivers because they have no other choice (Becker, 2007).

Caregiving by children can include domestic chores, childcare, intimate caregiving and general caregiving (Robson et al, 2006). Firstly, domestic chores can include tasks like cooking, washing clothes and dishes, fetching water and cleaning the house. Secondly, childcare can include washing school uniforms and accompanying siblings to school. Thirdly, intimate caregiving can include helping the care recipient to walk, bathe and dress, as well as giving the care recipient medication. Intimate care can also include providing the care recipient with emotional support (Skovdal et al, 2013). Even though emotional support is mentioned in some frameworks describing the roles of children in caring for their parents (e.g., Becker et al, 2001; Warren, 2007; Skovdal et al, 2013), what exactly the provision of emotional support means is not elaborated on. Finally, general caregiving can include bringing the care recipient to the hospital or other healthcare facilities, buying medicine, and giving the care recipient food (Robson et al, 2006).

In many African countries, domestic chores and childcare are seen as normal tasks that children can undertake, whereas intimate caregiving and general caregiving are specific tasks of young carers (Robson et al, 2006). When deciding on the appropriateness of these caregiving tasks, cultural norms and expectations of the role of children in the household should thus be taken into account (Skovdal et al, 2013). What is considered to be harmful in one culture might be considered a normal part of childhood or a normal responsibility for a child to have in another culture (Ribbens McCarthy & Gillies, 2017). For example, in many Western cultures there is a construction of childhood as a phase in life that is 'sacred' and should be protected, and mainly be spent playing, whereas in many other cultures it is considered to be normal for children, from a very young age, to carry out the same household duties as adults (Becker, 2007; Skovdal et al, 2013). Anecdotal evidence from various African countries suggests that the children who are caring for their parents are often between 8 and 11 years old, since older siblings are more likely to leave home in order to work and provide financial support for the family (UNAIDS, 2000).

In low-income countries, children whose parents have a disability often have to care for their parents because of reduced access to healthcare and lower incomes (Robson, 2004). Most young carers come from families that are likely to be living in poverty, are disadvantaged and socially excluded (Aldridge & Becker, 2003; Warren, 2007). Healthcare might be unavailable or unaffordable for the family. Furthermore, the community might not recognise the family's need for care (Becker, 2007). It has been suggested that the need for young people to care for their parents is a result of reduced healthcare from the state (Becker, 2007). The absence of public utilities, welfare services or social security requires caregiving children in Africa to perform many time-consuming and strenuous household labours that their parents are incapable of doing (Laird, 2005). Helping their family in meeting survival needs, and caring for them in times of sickness, is underpinned by a value system that sees it as an obligation for children (Laird, 2005).

There is a limited amount of literature available on parents with a disability (Olsen & Clarke, 2003). Research is often either on parents raising their child with a disability or on parents with a disability being cared for by their adult children. There seems to be limited attention to the situation where the person with a disability is both responsible for care and dependent on care (Olsen & Clarke, 2003). Even though insight into the role of young carers seems to be lacking the world over (e.g., Becker, 2007; Darling et al, 2019), low- and middle-income countries seem to be underrepresented in the currently available research. Despite several existing frameworks that describe the roles that children can have as young carers (e.g., Becker et al, 2001; Robson et al, 2006; Warren, 2007; Skovdal et al, 2013), there is limited information available about the factual roles that children have in caring for their parents with a disability and the relationship to poverty.

Objective

This research study aims to provide more insights into the role of children in caring for their parents with a disability in Sierra Leone and Cameroon.

METHOD

Study Design

Quantitative and qualitative data were collected, using two different questionnaires containing both open-ended and close-ended questions. These

questionnaires were specifically designed in order to get a clearer insight into the role that children have in caring for their parents with a disability in Sierra Leone and Cameroon. The first questionnaire, designed for parents with a disability, included questions about the parent's culture, disability, personal life, and the roles that their children, other family members and aid organisations have in their lives. The second questionnaire, designed for fieldworkers working with parents with a disability, included questions about the fieldworkers' experiences and opinions regarding the roles undertaken by children in caring for their parents with a disability.

Data Collection

Data collection took place in December 2020 and January 2021. The two different questionnaires were sent to professionals attached to organisations involved with people with disabilities in Sierra Leone and Cameroon. These professionals helped to distribute the questionnaires among 23 parents and 5 community fieldworkers. The study included parents with a disability who were living with at least one child. The age and gender of the children were not taken into consideration. No distinction was made between different kinds of disabilities (e.g., innate or acquired; physical, intellectual, sensory, or others). Since the questionnaires were in English, the community fieldworkers assisted the parents in understanding and filling them in.

Data Analysis

The quantitative data obtained from the close-ended questions was analysed using IBM SPSS Statistics (Version 27). Manual coding was used to categorise the responses that were given to the open-ended questions. The responses were analysed and reviewed by the two researchers, separately, before making a comparison. This was done to reduce the effect of personal filters that might affect the interpretation of the responses given.

Ethical Considerations

All respondents gave their written consent to participate in this study.

RESULTS

Questionnaire for Parents

The questionnaire for parents was completed by 23 respondents. Two parents did not meet the study's inclusion criteria and were excluded. The remaining 21 respondents included 3 parents from Sierra Leone and 18 parents from Cameroon. While 10 of the 21 parents had innate disability, 16 of them stated that their disability requires someone else to care for them. The respondents had between 1 and 13 children ($M = 4.0$; $SD = 2.86$).

Although 9 of the 21 respondents had a job, none of the respondents reported having an income that could meet their own or their family's basic needs. In addition, 10 of the 21 respondents had a partner, but none of them reported that their partners had a job.

The participants were asked to describe how they thought their children could or should support their parent with a disability. One respondent did not specify the type of support wished for and another respondent mentioned that his/her children were too small to provide support. Fourteen of the 19 respondents who specified the kind of support their children could or should provide, mentioned domestic chores like preparing food, fetching water and cleaning. One of the 19 respondents mentioned childcare, like assisting some of their children with school needs, as a type of support. In addition, 5 of the 19 respondents mentioned intimate caregiving, like helping the parent with a disability to walk and giving advice. General caregiving like providing financial support and running errands was mentioned as a type of support by 7 of the 19 respondents.

When asked about the emotional support provided by their children, the respondents often answered that they experienced this when their children encouraged them, helped when needed, and showed compassion. Parents also received emotional support when their children reassured them, showed affection, or obeyed them.

Fourteen of the 21 parents stated that their children attend school, while 5 parents said that some of their children attend school. Among the reasons for not attending school were poor results and dropping out in order to provide money for the family. Of the 19 children who did attend school, 16 were doing well in terms of grades in school and comprehension, as reported by their parents. It should be noted that it is unclear whether any of the children performing well in school also had a role as a young carer.

Seven of the 21 respondents reported that their children work. The work that children performed were domestic tasks, like fetching water and cleaning houses,

helping in the business of their parents, or farming. The main reason for working was to support the family in basic needs. One parent mentioned that the child works for fun. Only 3 of these 7 respondents answered the question “How many hours does your child work per week?”, so this question has been excluded from the data.

Kind of Support

Nine of the 10 respondents who had a partner stated that their partner/spouse helped in raising the children. Their help in child-rearing involved preparing food, washing clothes, taking care of their children whenever the children were sick, and helping their children in education by paying for schooling, transporting the children to school or helping in the process of education itself. Fourteen of the 21 parents also reported that their children received support from other people, such as family members, friends, aid organisations or community members, even though the kind of support was not specified.

Except for one parent, the rest of the 21 respondents felt they needed more help in raising their children. It is noteworthy to mention that the one respondent who indicated there was no need for more help, however wanted more livelihood support for business. Two respondents did not specify what kind of help they wished for. Seventeen of the 19 respondents who answered the question “What kind of help do you wish for?” asked for some kind of financial support. They would use this support either to expand their business, which would enable them to provide their family with basic needs, or to finance their children’s education. Besides financial support, 2 respondents wished for a personal assistant to either support their children in school or to support them in their business so their children can focus on their education. Three of the 19 respondents wished for support in obtaining resources like books and clothes.

Six of the 21 parents mentioned that an aid organisation was helping them. Four of these respondents received financial support to start up or grow their business, and the other 2 respondents mentioned receiving livelihood support. One respondent added that a mobility aid like crutches was received.

Only 10 of the respondents noted that healthcare was available for them and their families; however 18 respondents stated that they could not afford healthcare.

Questionnaire for Fieldworkers

The questionnaire for fieldworkers was completed by 5 respondents – one was a fieldworker from Sierra Leone and 4 were from Cameroon. All 5 of them had worked with children who had parents with a disability.

Two of the 5 fieldworkers considered that caring for parents with a disability was the responsibility of the child. One respondent stated:

“One gets blessed if you serve your parent. If one’s parent has a disability, you see it as your responsibility to do your best for them so you get blessed. It’s a common practice”.

The respondent from Sierra Leone said that children should give their parents any kind of support they may need, depending on the severity of the impairment. This answer was similar to the answers given by some of the fieldworkers from Cameroon. However, the other 2 fieldworkers from Cameroon mentioned that this can be regarded as a burden on the children. This indicates that the fieldworkers have diverse opinions.

If the child caring for a parent with a disability is under 18 years of age, 3 of the 5 respondents would consider this as child labour. When a child is 18 years or older, none of the respondents would consider caring for a parent with a disability as child labour. It should be noted that the respondents did not specify what kind of care they considered to be work.

There were mixed answers regarding whether girls or boys were more likely to take financial care of their parent with a disability. Two fieldworkers felt that daughters were more likely to do so, whereas 1 fieldworker attributed this task to sons. However, 2 fieldworkers mentioned that daughters and sons were equally likely to take financial care of their parents with a disability. Interestingly all 5 fieldworkers mentioned that daughters and sons were equally likely to take care of their parents at home. One respondent noted that the sex of the parent influenced whether their sons or daughters took care of them. Male children seemed to be carers for their fathers, while female children seemed to take care of their mothers.

Fieldworkers had different ways of defining the provision of emotional support by children. Four of them regarded showing compassion as a sign of emotional support. Examples cited were of children taking an interest in the disability, showing that they were proud of their parents, and accepting the parent’s condition. Furthermore, 2 participants stated that offering encouragement and providing help were aspects of emotional support. One participant thought a show

of affection, such as hugging, was also emotional support. All the respondents felt that more research was needed on children who have to care for their parents with a disability. In addition, all of them believed that NGOs had to do something to prevent children under 18 years from working. The fieldworkers stated specific actions that NGOs could take, such as provision of financial support, livelihood support, provision of personal assistants to the parents, educational support for the children, and support from community members.

DISCUSSION

This research article aimed to answer the question: “What is the role of children in caring for their parents with a disability in Sierra Leone and Cameroon?” .

It was found that children take on several roles when caring for their parents with a disability. With regard to the types of support that parents with a disability believe their children could or should provide, support most often mentioned was help with domestic chores like preparing food, fetching water and cleaning. Other types of support mentioned were intimate caregiving, like helping the parent to walk and giving advice; childcare, like assisting their siblings with school needs; and general caregiving, like providing financial support and running errands. Emotional support that parents received most often took the form of children’s encouragement and helping when needed, and showing compassion. They also experienced emotional support when children reassured them, showed affection, or obeyed them.

As to the effect that the caring role has on children, most children reportedly were able to attend school, even though some parents could only send some of their children to school. The reasons for not attending school were poor results and the need to provide money for the family. Caring for parents was not found to have an impact on children’s achievements at school since most of the children were reportedly doing well academically. However, as mentioned before, it is unclear whether those who were performing well in school were also parental caregivers. One-third of the parents reported that their children work, the main reason being to support the family’s needs. Even though nearly half of the parents worked, none of them earned enough to meet their own basic needs or the needs of their family.

All but one of the respondents believed that more help in raising their children was needed, despite help received from partners, family members, friends, aid

organisations or community members. The majority also wished for some kind of direct or indirect financial support to expand their business or finance their children's education. In the minority were parents who had received financial or livelihood support from an aid organisation. Healthcare was found to be available for about half of the parents, but only a few could actually afford it.

To supplement the data collected from the parents, a questionnaire was also completed by fieldworkers. The fieldworkers interpreted the caring role of children in different ways, judging it variously as a responsibility, a blessing, or a burden. Regarding the gender specificity of tasks, no clear conclusions could be drawn. Similar to the parents' opinion, the fieldworkers defined emotional support by children as the showing of compassion and affection, and the provision of help as well as encouragement. About half of the fieldworkers felt that it was child labour if children under the age of 18 years were caring for their parents with a disability. All the respondents believed that more research had to be done on children who are caregivers for their parents with a disability. Possible actions that NGOs could undertake to prevent underage children from working were mentioned, such as offering financial or livelihood support, providing a personal assistant for the parents, supporting the children in their education, and increasing the support from community members.

Implications

This study has shown that in low- and middle-income countries such as Cameroon and Sierra Leone, children are often caregivers for their parents with a disability. The roles that children can have are diverse. They are expected to undertake domestic chores, and provide childcare, intimate caregiving, and general caregiving. These roles correspond to the roles found in previous research (Robson et al, 2006). However, unlike previous research (Robson et al, 2006), childcare was mentioned by only 1 parent in this study. A possible explanation for this finding could be that the parents were asked to describe the types of support that children could or should provide them, rather than the tasks that they in fact carry out. This could therefore signify a discrepancy between the tasks that children are expected to carry out and the tasks that are actually carried out. Future research could look into this possible discrepancy. Emotional support, which can be seen as part of intimate caregiving, has not been elaborated on in the previous research. Therefore, participants were asked for their definition of emotional support. It was found that parents mostly experienced emotional

support in the form of their children's encouragement, compassion, affection, reassurance, and obedience. Future research could take these components into account when investigating the emotional support offered by children.

It was found that the majority of the parents with a disability needed more help in raising their children. The implicit message is that parents would appreciate additional help so that their children might have to perform fewer caregiving tasks. Since no distinction was made in this study between small and large families, future research could look into the caregiving burden of large families (i.e., when there are more children sharing the caregiving burden, the burden may be smaller and thus affects them less, or at least in a less negative way). It has previously been suggested that the appropriateness of the provided care is dependent on the care that is provided, the intensity of the caregiving, and its frequency (Becker, 2007). According to Gibson et al (2019), when a young carer is identified, the local authority could inspect whether the care the young carer provides is appropriate or not (Gibson et al, 2019). Whenever the conclusion is that the care the child delivers is inappropriate, the local authority has to provide suitable support for the parent. If the parent receives support, this will lead to a reduction of the care the young carer has to provide (Gibson et al, 2019).

When determining which children need extra support, it is important that people working in the field consider cultural norms and universal children's rights about a child's care responsibilities. In this study, it was found that caring for a parent with a disability is sometimes seen as the responsibility of a child. In Western cultures children are not expected to take responsibilities in substantial or regular caring (Becker, 2007), whereas this might be 'normal' in some cultures. To prevent an incomprehensible gap about whether caring for a parent with a disability is or is not appropriate, different cultural norms have to be mapped in future research and compared to children's rights and child protection.

Suggested ways in which NGOs can support parents with disabilities were by providing them with personal assistants or engaging them in sustainable livelihood programmes which are another way of empowering families economically (OneFamilyPeople, 2016). The provision of personal assistants might not be realistic due to the costs involved and the fact that it is not a long-term solution, unless it is possible to give parents a personal assistant for their whole lives. Economic empowerment through sustainable livelihood programmes might therefore be a more viable and sustainable option. Conforming to the empirical analysis, parents with a disability might be more independent when

they receive a business grant from an aid organisation. Besides, according to the empirical analysis, it might be helpful if an aid organisation assists with educational materials and housing. As has been mentioned by the fieldworkers, aid organisations can also help in providing general educational support and basic needs for the children. It is recommended that aid organisations or NGOs keep in mind the needs of parents when deciding on the kind of help to be provided, as well as the feasibility of certain solutions.

The empirical analysis showed that healthcare is not always available for parents. This finding is in line with that of Becker (2007) who stated that healthcare might be unavailable. In fact, even when healthcare is available, analysis showed that the majority of the parents could not afford it. Future research should focus on the availability of healthcare and assistive devices in different regions, the time people have to travel to get healthcare and the quality of the available healthcare. For parents with a physical disability an assistive device might make the parent more autonomous, relieving the child from providing extensive care. Future research should map the availability and usability of assistive devices in Africa. Service provision, such as from fieldworkers, should be included in future research as well, since it is sometimes one of the only alternatives for people in rural areas in low and middle-income countries who do not have access to healthcare. It is important to consider the possible obstacles to availing of healthcare (e.g., travelling time, access, financial issues). Financial issues have to be taken into account and families who cannot afford healthcare should get financial support to do so. Future research should investigate how poor families can get more financial support and thereby improve access to healthcare.

Since none of the parents reported having an income that meets their basic needs or the needs of their families, young carers might have to deal with poverty, which is in line with findings from the DFID (2000). When children live in poverty, they might not be able to pay for schooling. In addition, several parents had to let their children work in order to meet basic needs. However, there is limited literature available about this possible link. Future research should focus on the possible link between young people having to care for a person with a disability and child labour, and the possible link between having a disability and poverty.

Limitations

This study suffers from a few limitations. First, the largely open-ended questions in the questionnaires might have led to differing interpretations and consequently

to variations in the given answers. When big differences in the interpretation of a question were found, the question was judged to be invalid and was excluded from the results. However, some differences in interpretation might not have been spotted, and could therefore have influenced the results. Second, the questionnaire was in English, so some of the parents needed assistance from fieldworkers to complete the questionnaire. It is possible that since an intermediary was involved, the parents may not have answered some of the sensitive questions honestly. Another consequence of the language barrier could be that the questions may not have been understood in the way that was intended. Wherever any misunderstanding was obvious, the given answer was excluded from the results; however, this might not always have been obvious and could have influenced the results. Third, the results showed outcomes for children which were based on data provided by parents and fieldworkers, without taking into account the children's views. The viewpoint of children could be included in future research for a more complete picture. Fourth, the age and gender of the children were not investigated. Future research could give more clarity about possible gender-related differences in caregiving. Fifth, the interpretation of the given answers was done by just two researchers. Even though researchers did the coding of the results independently before comparing the results, bias or personal filters could have affected the way in which the given answers were interpreted. There was no significant difference between the two researchers. Lastly, this study was based on a limited sample size, so the findings should be interpreted carefully. In addition, since the majority of the respondents were from Cameroon, the results should be interpreted extra carefully for Sierra Leone.

CONCLUSION

Even though young carers are a large group, there is a lack of literature about the role of children in caring for their parents with a disability in Sierra Leone and Cameroon. When there is more insight into the role of young carers, they can receive help which might prevent negative effects. The research results show that children take on several roles when caring for their parents with a disability, like domestic chores, intimate caregiving, childcare and general caregiving. Parents with a disability wish for more help in raising their children. Young carers might have to deal with poverty and several parents let their children work in order to meet their basic needs. Future research should map cultural norms and expectations about a child's caregiving responsibilities, and focus on aspects that are associated with these tasks among young carers.

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REVIEWS

Community-Based Rehabilitation in Settings of Armed Conflict, Natural Disaster, or Mass Displacement: A Scoping Review

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ABSTRACT

Purpose: CBR approaches have been implemented in many countries and a wide range of settings. This study aimed to synthesise knowledge available in the scientific literature about health-related CBR programmes in settings affected by armed conflict, natural disaster or mass displacement.

Method: Databases searched in this scoping review were MEDLINE, CINAHL, EMBASE, PsycInfo and Google Scholar. Articles were included if they focused on health-related CBR undertaken in communities affected by armed conflict, natural disaster or mass displacement. Descriptive statistics and qualitative content analysis were used to analyse the selected articles.

Results: Of the 5537 articles screened, 31 met the eligibility criteria. Collectively, they address diverse CBR programmes across crisis settings. Factors that promoted successful CBR implementation were strong community and family support, and the development of CBR activities tailored to local cultural and social contexts. Barriers included human resource limitations and insufficient collaboration. Authors of the selected articles made recommendations for CBR implementation in crisis settings, including prioritising efforts to enhance community involvement, investment in crisis preparedness, initiatives to increase disability awareness, and the adoption of long-term management

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strategies.

Conclusion: *CBR programmes can make important contributions in crisis settings. Community involvement and access to resources are crucial for programmes to effectively respond to the needs of the individuals and communities they aim to serve and for the sustainability of these initiatives. The findings of this review can help to inform CBR stakeholders regarding opportunities and challenges for developing and carrying out CBR programmes in crisis settings, including initiatives to establish guidance or policy.*

Key words: *persons with disabilities, health, programmes, implementation*

INTRODUCTION

Community-based rehabilitation (CBR) is “a strategy within general community development for the rehabilitation, equalisation of opportunities and social inclusion of all people with disabilities” (International Labour Office, UNESCO, WHO, 2004). It was initiated by the World Health Organisation (WHO) following the International Conference on Primary Health Care in 1978 (Khasnabis et al, 2010). The scope of CBR has since widened and is now understood as a multisectoral strategy that addresses the broader needs of persons with disabilities and supports their participation and integration into their communities (Khasnabis et al, 2010). CBR programmes aim to improve the overall quality of life of persons with disabilities (Khasnabis et al, 2010). As of 2010, CBR programmes had been implemented in over 90 nations worldwide, mostly in low- and middle-income countries (Khasnabis et al, 2010).

Humanitarian crises are situations where there are widespread and elevated threats to the health and well-being of populations. They may result from a sudden, recurrent or progressive disaster, or due to armed conflict or political instability. Such events may spur mass displacement of populations within countries or across national borders (Kirbyshire et al, 2017). In crisis settings, persons with disabilities are at elevated risks of experiencing harm, including separation from caregivers, exclusion from registries or shelters, loss of assistive devices, barriers to mobility, inaccessibility of services, and heightened risk of exploitation and abuse (WHO, 2011).

CBR approaches may already exist in settings where a crisis occurs, or could be initiated while a crisis is ongoing or in its aftermath, thus providing assistance and support to persons with disabilities who are caught up in an emergency (Eide,

2010). Boyce, Koros and Hodgson (2002) described the positive impacts of CBR projects on civil society initiatives, promoting economic and social reconstruction in settings affected by an armed conflict. CBR programmes in crisis settings can support people with long-standing disabilities, as well as persons who experience the onset of a new disability due to an injury or illness which may be exacerbated by limited access to care and assistance. Most refugees are displaced to neighbouring low- or middle-income countries, where access to services and support may also be limited, increasing the likelihood of people experiencing increased impairment and barriers to participation (Landry et al, 2020). While CBR programmes are implemented in various humanitarian crisis settings, their application has distinctive challenges and potential benefits in contexts affected by war, disaster or displacement.

Objective

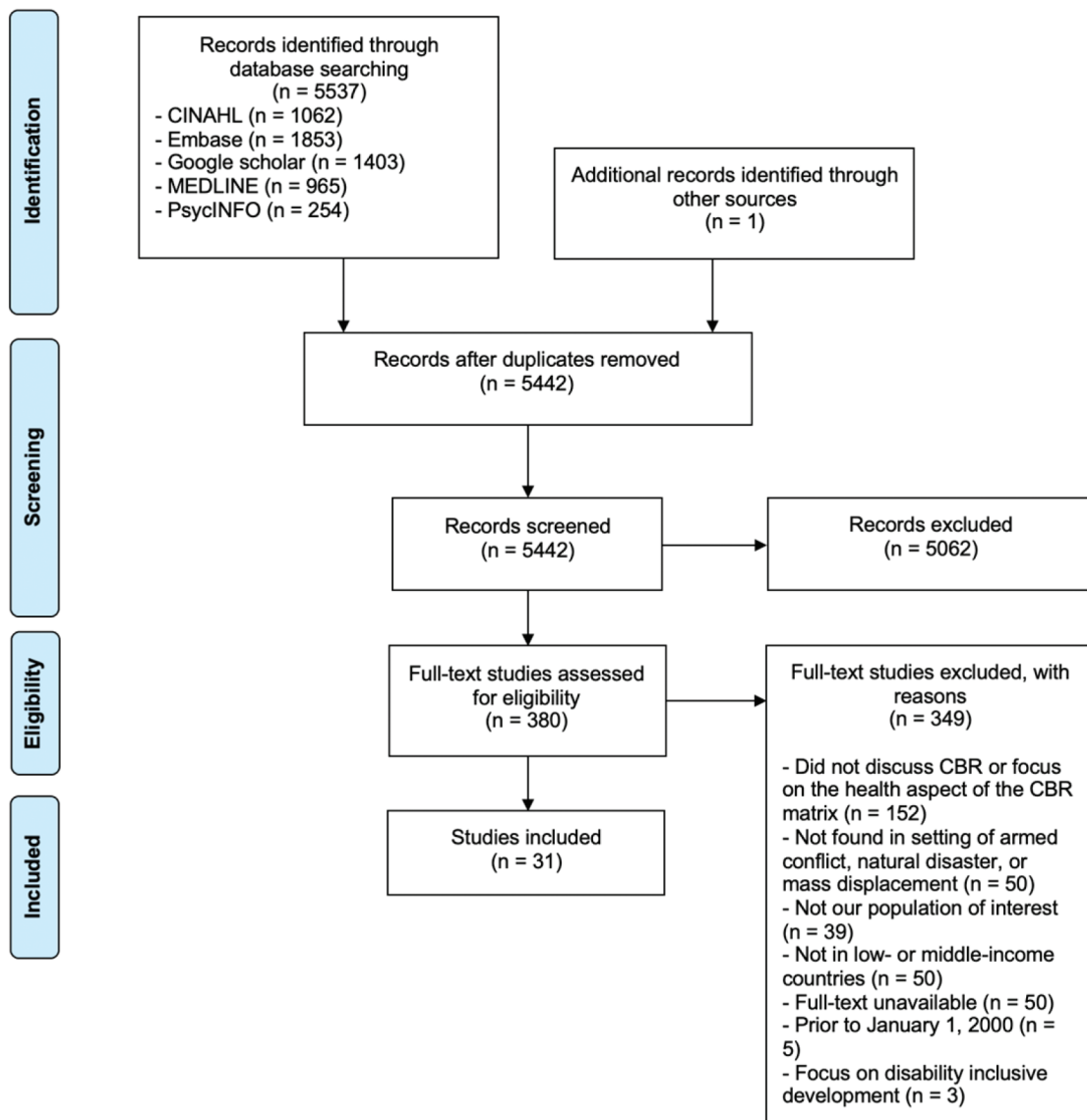
The authors of this article undertook a scoping literature review to appraise academic literature regarding the implementation of CBR in settings affected by a natural disaster, armed conflict or mass displacement.

METHOD

Study Design

The methodological framework of Arksey and O'Malley (2005) guided the development of a scoping review to answer the question, "What is known about the implementation of CBR in situations of armed conflict, natural disaster or mass displacement?" The review process is presented in an adapted Preferred Reporting Items for Systematic Reviews and Meta-Analyses chart (see Figure 1). Detailed descriptions of actions taken during the five stages of the scoping review are summarised below and in Supplementary Table 1.

Figure 1: PRISMA Flow Diagram: Processes for Study Screening, Eligibility and Inclusion



Note: PRISMA = Preferred Reporting Items for Systematic Reviews and Meta-Analyses; CBR = community-based rehabilitation

Supplementary Table 1: Stages involved in the review process

Stages	Actions involved
Stage 1: Identifying the Research Question	Through frequent meetings and discussions, MH and SM developed the concept note for the review. The review team met to determine the research question, secondary objectives, selection criteria, and database search. The research question developed through iterative steps was, <i>“What is known about community-based rehabilitation (CBR) in settings affected by armed conflict, natural disaster, or mass displacement?”</i> The secondary objectives guiding this scoping review were: (1) to examine how CBR approaches are implemented in settings affected by armed conflict, natural disaster, and mass displacement; (2) to evaluate how CBR has an impact in those settings; (3) to identify the barriers and facilitators of CBR implementation in the aforementioned settings; and (4) to identify the gaps in knowledge in the literature about CBR in these settings. Due to the extensive nature of CBR, the health domain of the CBR Matrix (Khasnabis et al, 2010) was selected as the focus for the review.
Stage 2: Identifying relevant articles (Search Strategy)	The search was performed using four electronic databases: CINAHL, EMBASE, MEDLINE, and PsycInfo. Google Scholar was also searched for publications, using terms such as CBR, armed conflict, natural disaster, and mass displacement. The Medical Subject Headings terms and keywords used were armed conflicts, human migration, natural disasters, community health services, war, bombing, immigration, forced displacement, massive evacuation, disability inclusive development, and rehabilitation approaches. Boolean operators “AND” and “OR” were used to retrieve relevant literature.
Stage 3: Study Selection	Inter-rater reliability was established on a pilot set of 100 articles. Articles were selected by DL, JK, AM and MV using an iterative approach. Each study was reviewed for relevance, and the reference lists and citations were also reviewed to identify other relevant papers. This process identified one publication (Eide, 2010) through a review of an excluded publication (Martz, 2010).
Stage 4: Charting the Data	A data charting form (Table 1) was collectively developed by the review team. The data extraction process was iterative in nature, where we continually extracted data and updated the data charting form throughout our scoping review. DL, JK, MV, AM independently extracted data from the first ten articles using the data charting form and then met to determine if their approach to data extraction is consistent with the research question, and to ensure that relevant information is being extracted. They then combined their findings in the data charting form. Reviewers DL and JK extracted the data from the articles selected from CINAHL, MEDLINE and Google scholar. AM and MV completed the same process for articles found in Embase and PsycInfo.
Stage 5: Collating, Summarising, and Reporting the Results	The extracted data was documented in Microsoft Excel and digitally collated using a Microsoft Office OneDrive. The analysis for this review included descriptive numerical summary analysis and qualitative thematic analysis (Levac, Colquhoun & O’Brien, 2010). The descriptive numerical summary described the characteristics of the articles, including bibliographic data, types of study methods, geographic locations and level of income of the countries where the research was conducted, the number of physical and mental health initiatives found in the articles, and the various settings (armed conflict, natural disaster, mass displacement) of the included articles. An inductive technique was used to interpret the findings by analysing the themes found. Data was coded, emerging themes were identified, and a concept map was created. Emerging themes were identified by observing patterns and the frequency in which they appeared to answer the research question, such as barriers and facilitators to CBR implementation and the effectiveness of CBR programmes. The results were reported through tables, graphs and figures. The draft of the reports was discussed through email and virtual meetings and finalised by the review team.

Data Collection

The review included peer-reviewed articles on CBR interventions in armed conflict, natural disaster, or mass displacement settings.

Inclusion criteria:

- Articles that aimed to address health-related CBR activities in a crisis setting in a low- or middle-income country, involving children or adults with mental or physical disabilities, as well as families, communities, care providers, policymakers and others involved in CBR.
- Empirical and non-empirical articles, irrespective of study design.
- Only English language articles published between January 2000 - July 2021, after screening for relevance to the health domain of the CBR Matrix (Khasnabis et al, 2010).

The search was performed in July 2021 in four electronic databases: CINAHL, EMBASE, MEDLINE, and PsycInfo. Medical Subject Headings related to armed conflicts, human migration, natural disasters, and community health services were used in the search, along with keywords (e.g., war*, bombing*, immigration*, forced displacement*, massive evacuation*, disability inclusive development, and rehabilitation). Google Scholar was searched using terms such as ‘community-based rehabilitation’, ‘armed conflict’, ‘natural disaster’ and ‘mass displacement’. The Boolean logic for the search is as follows: Community-based rehabilitation AND (armed conflict OR mass displacement OR disaster). EndNote was used to organise the screening process.

Two teams of two reviewers each screened titles and abstracts. Inter-rater reliability was established between reviewers, using a pilot screening of 100 MEDLINE and Google Scholar publications. The teams discussed their assessments and collaboratively decided to address discrepancies, achieving 90% consistency. Abstracts and full texts of all the retained articles were reviewed. This step was again conducted in pairs. Discrepancies were reviewed and resolved in discussion with other team members. The reference lists and citations of selected articles were then reviewed to identify other relevant papers.

A data charting form was collectively developed and refined iteratively using Microsoft Excel (see Table 1). It included bibliometric (e.g., journal, authors, publication date), contextual (e.g., location, type of humanitarian crisis), and substantive (e.g., barriers and facilitators to implementing CBR) information.

The first four authors independently extracted data from 10 articles and then compared their tables in consultation with their other two colleagues. Differences were discussed, a consensus on how to proceed was arrived at, and the remaining articles were then divided among them to complete data extraction.

Table 1: Data Extraction Form

Bibliographic data	Context and methods	Results
Author(s)	Study design/type of article	Barriers of CBR implementation
Year of publication	Purpose/objectives(s)	Facilitators of CBR implementation
Authors' affiliation location compared to CBR location (local or international)	CBR setting (armed conflict, natural disaster, and/or mass displacement)	Recommendations by the authors
Journal	Geographic location (country)	Miscellaneous (relevant information to be used in the background)
	Country's level of income	
	Description of CBR programme	
	Participants (type of physical and/or mental disability)	
	Specific component of the health aspect of the CBR Matrix (promotion, prevention, medical care, rehabilitation, and/or assistive devices)	
	CBR intervention or programme	

Note: CBR = community-based rehabilitation

Data Analysis

Analysis of the extracted data included basic descriptive statistics and qualitative content analysis (Levac et al, 2010). For the qualitative analysis, an inductive-deductive approach was used. Open coding was applied within the categories of the data extraction Table. Patterns and linkages were then identified based on the codes, creating a concept map of related topics and considerations, and guiding the development of themes.

RESULTS

Identification and Selection of Articles

The initial search yielded 5,537 documents. After removing duplicates, screening and selection, 31 articles were included in the final analysis. The retained articles

address a range of humanitarian crisis settings globally. They include 20 articles focused on specific countries, 9 articles with a global scope, and 2 that were not specific about their sphere of application.

Where articles identified a specific country of focus (see Figure 2), India featured the most often (4 articles), followed by Bosnia and Herzegovina, China, Nepal and Sri Lanka (2 articles each). In terms of the level of income, according to the World Bank Group (n.d.), lower- or middle-income countries were the most prevalent (13 articles), followed by upper middle-income countries (5 articles) and low-income countries (2 articles). The articles most frequently addressed natural disasters (17 articles), followed by armed conflicts (10 articles), with few articles discussing mass displacement or a mix of crisis settings (see Figure 3). Common areas of focus for the articles include implementation processes for CBR programmes, facilitators and barriers to implementation of CBR, and recommendations for future implementation of CBR programmes.

Figure 2: Summary of Geographic Locations in Included Articles

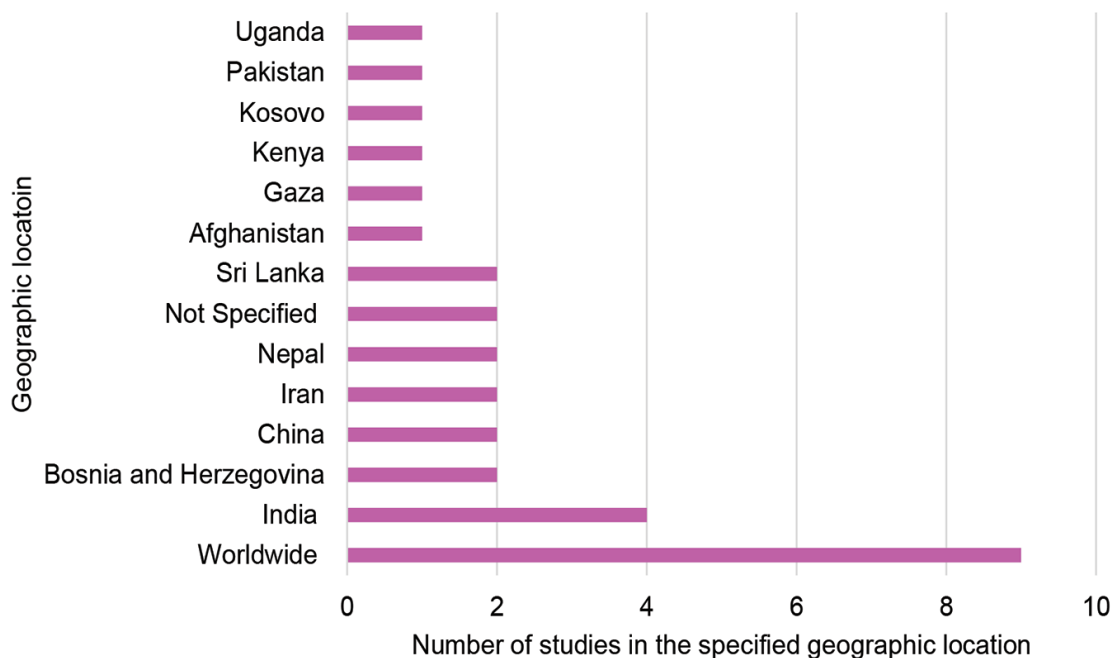
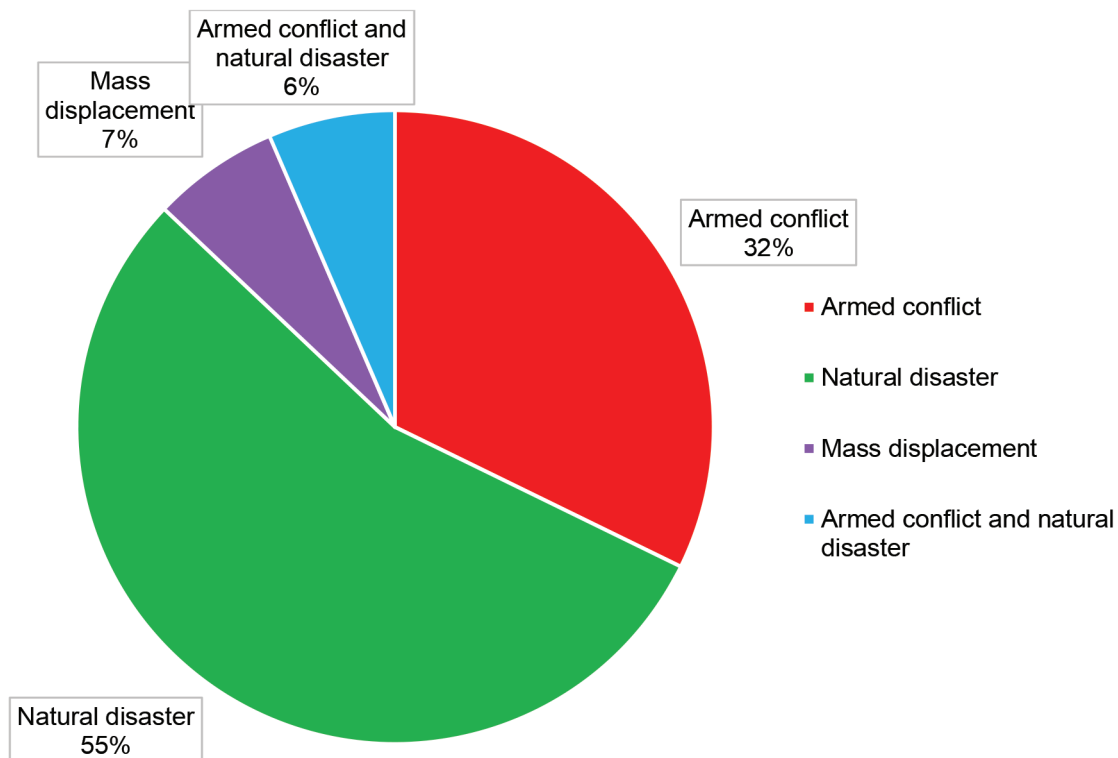


Figure 3: Summary of CBR Settings in Included Articles



Note: CBR = community-based rehabilitation

Implementation of CBR programmes in Armed Conflict Settings

In several armed conflict settings, organisations of people with disabilities (OPDs) have played significant roles in delivering CBR for persons with disabilities (Eide, 2010). For example, Masateru, Soosai and Robert (2017) assessed a CBR programme implemented by OPDs in Sri Lanka after the civil war, which included medical support, physical therapy, assistive devices, and livelihood supports. Positive outcomes on the quality of life of persons with disabilities, such as improved socioeconomic conditions, were found post implementation. For example, a female who had a physical disability due to a war injury explained that as a result of the CBR programme, she was able to purchase a sewing machine which she uses as a source of income for her family following the death of her husband due to the conflict (Masateru et al, 2017). In Afghanistan, CBR committees were implemented by community rehabilitation and development workers trained by the WHO, United Nations International Children’s Emergency Fund,

and local and international non-governmental organisations (NGOs) (Coleridge, 2002). They implemented the Comprehensive Disabled Afghans Programme, which aimed to identify and refer persons with disabilities to appropriate services, provide home-based training, and educate the community on the issue of disability (Coleridge, 2002).

Implementation of CBR Programmes in Natural Disaster Settings

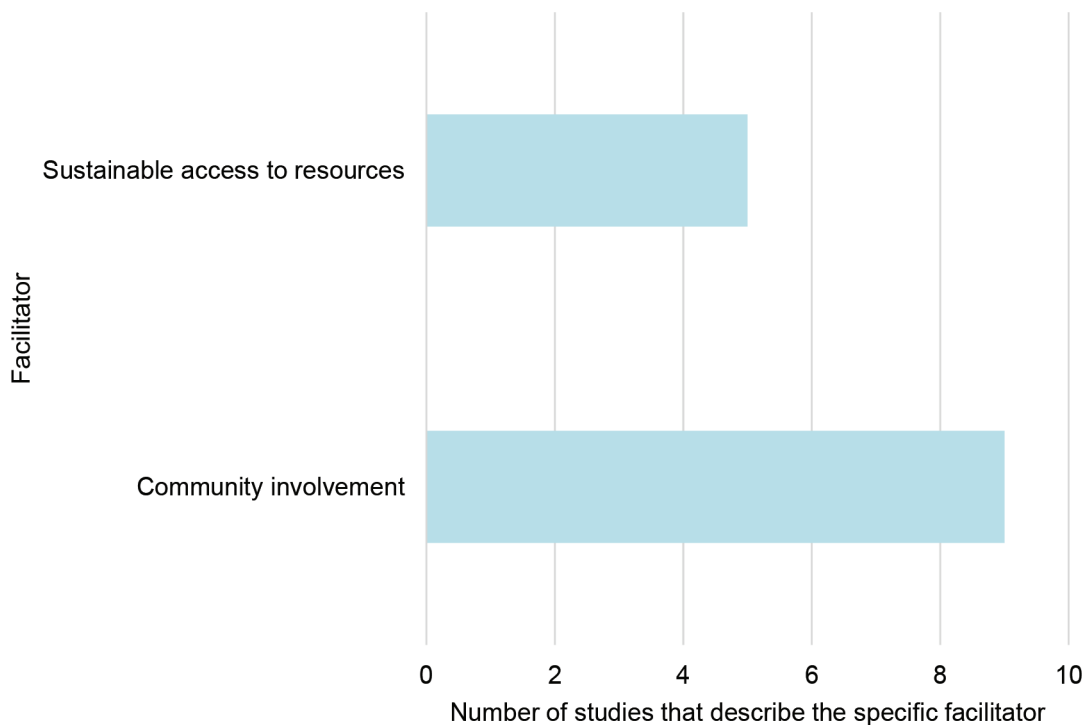
The selected articles highlight how the increase in healthcare needs, including new injuries resulting in disabilities, could lead to implementing new CBR programmes after a disaster. For instance, after the Sichuan earthquake in 2008, a CBR programme including CBR health services was implemented by the Chinese Association of Rehabilitation Medicine, local health ministries and NGOs (Gosney et al, 2013; Zhang, Reinhardt & Gosney, 2013). Following the 2004 tsunami, the government of India implemented a programme providing a psychosocial model of care through the National Institute of Mental Health and Neurosciences. Workers from governmental agencies, NGOs, and members of the affected communities participated in these responses (Becker, 2007; Kasi, Bhadra & Dyer, 2007; Math et al, 2008).

Implementation of CBR programmes in Mass Displacement Settings

In situations of mass displacement, the United Nations High Commissioner for Refugees (UNHCR) manages CBR programmes. For example, in the Dadaab refugee camp in Kenya, CBR implementation for Somali refugees was managed by the UNHCR in collaboration with two NGOs responsible for health care in the camp - CARE Kenya and Gesellschaft für Technische Zusammenarbeit. The programmes aimed to facilitate rehabilitation by providing basic therapy interventions, inclusive education, and the provision of assistive devices such as wheelchairs, prosthetics, and other mobility aids (Wee, 2010).

Facilitators to Implementation of CBR

Several factors supported or fostered successful CBR interventions in humanitarian crisis settings. The most common facilitators were community involvement and sustainable access to resources (see Figure 4).

Figure 4: Summary of Frequent Facilitators Reported in Included Articles

Community Involvement - The crux of CBR programmes is reliance on community empowerment and involvement. This enables sustainability of the programmes, especially in crisis settings. Paradoxically, it may also be most challenging to achieve this in such settings. Evidence suggests that community values, culture, religious beliefs, and rituals were essential contributions through community involvement across crisis settings. Agani, Landau and Agani (2010) highlighted the importance of drawing on community resources, values, themes of previous generations and culture to bring the community together and promote resilience. They also reported that connecting with family and cultural values can help reduce post-traumatic stress, risk-taking behaviour, addiction, depression, and violence, to help protect against trauma. Ertl et al. (2011) assessed the efficacy of a community-based intervention targeting post-traumatic stress disorder (PTSD) symptoms in former child soldiers in Uganda. The therapy effectively reduced post-traumatic stress disorder symptoms when it was carried out by locally-trained community therapists (Ertl et al, 2011).

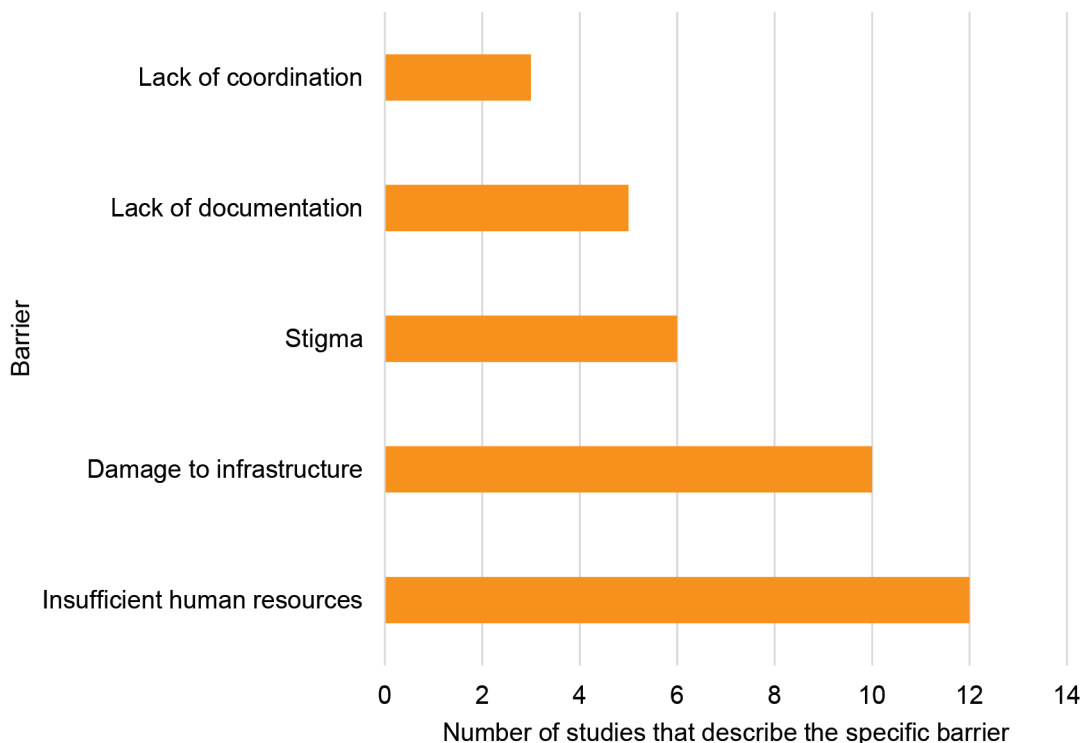
Following an earthquake and tsunami in the Andaman and Nicobar Islands, factors such as family support, attention to culture and incorporation of religious activities were identified as strategies that contributed to resilience among those affected by the crisis and helped them cope with their grief (Math et al, 2008). These aspects were also identified in relation to who was involved in providing care. In India, trained local community workers, who have more awareness of community needs, language, and culture, provided psychosocial care to survivors and ensured continuity of services after the 2004 tsunami (Becker, 2007).

Sustainable Access to Resources - Access to resources in a sustained manner is a key facilitator for robust and durable CBR programmes in crisis settings. Where programmes are not dependent on external support, they may be more sustainable. Coleridge (2002) reported that in Afghanistan where supply chains were disrupted, one of the major facilitators contributing to the CBR programmes' success and sustainability was its relative independence from external resources, with re-supply only required every six months. In Bosnia and Herzegovina, Edmonds (2005) stated that CBR "is sustainable because it is a government supported programme," which provides the possibility of a consistent and reliable provision of resources.

On the other hand, when the state structure is weakened, the fact that NGOs run a CBR programme can contribute to maintaining services during crises. Eide (2010) explains that in the West Bank and Gaza, even though the population was restricted in their movements because of the conflict with Israel, CBR services were still offered because local and regional self-driven structures were established. Combined with modern communication technology, these structures could continue functioning despite the movement restrictions imposed due to the conflict.

Barriers to Implementation of CBR

Most articles (n = 20) discussed barriers to implementing CBR programmes in crisis settings. The barriers most frequently reported were: a lack of coordination between programmes or stakeholders, insufficient human resources, lack of documentation, damage to infrastructure, and stigma against participants in CBR programmes (see Figure 5).

Figure 5: Summary of Frequent Barriers Reported in Included Articles

Lack of Coordination between Programmes or Stakeholders - Coordination and collaboration are fundamental challenges in many crisis settings, including coordination between international and national organisations and teams (Bailey, 2003; Sheikhbardsiri et al, 2017; Amatya et al, 2020). In a disaster setting, such gaps may result in difficulties in harmonising approaches to ensure needed support and establishing strategies before exiting, affecting long-term care (Amatya et al, 2020). Bailey (2003) reports that a lack of coordination between international programmes and local NGOs impeded the rehabilitation of persons affected by landmines in Bosnia and Herzegovina, and contributed to redundancy among assistance programmes.

Insufficient Human Resources - Many articles mentioned the lack of trained personnel as the main challenge to the successful implementation of CBR (Bailey, 2003; Math et al, 2008; Sadeghi & Ahmadi, 2008; Howard et al, 2012; Schnabel, 2013; Jeong et al, 2016; Landry et al, 2016; Sheikhbardsiri et al, 2017; Mousavi et al, 2019; Amatya et al, 2020). After the 2004 tsunami in India, health professionals

at a relief camp lacked training and knowledge related to mental health (Math et al, 2008). As a result, they were ill-equipped to address the population's mental health or psychosocial needs (Math et al, 2008). Mousavi et al. (2019) also reported that a lack of training related to disasters (at the university level) among rehabilitation professionals impeded their participation in these settings. An essential factor highlighted in the articles concerning natural disasters in India, was the importance of rehabilitation professionals' training and its availability. The lack of training, especially on injuries and pathologies that can be aggravated during natural disasters, contributed to the healthcare system not being equipped to effectively deal with survivors of natural disasters (Bailey, 2003). In mass displacement settings, a lack of access to trained professionals was also a major barrier (Gruner et al, 2020). Since refugees flee their home country, they are in a new environment and may not know how to effectively navigate the healthcare system of the host country. Furthermore, lack of trust in refugee camp administration, experiences of discrimination, a sense of insecurity and stigma against persons with disabilities, were barriers presented in the articles.

Lack of Documentation - In crisis settings, the availability, accessibility, and quality of documentation can pose a challenge for continuity of care (Chase & Bush, 2002; Kucukalic et al, 2005; Reinhardt et al, 2011). Health records may be inconsistently kept or not transferred at discharge. In other cases, international organisations may not provide documentation to national agencies when ending their programmes (Reinhardt et al, 2011). Reinhardt et al. (2011) also described how poor record-keeping can decrease the quality of epidemiological data needed to understand the impact of a disaster on the population and, in particular, persons with disabilities.

Damage to Infrastructure and Economic Destruction - During armed conflict and disaster, a major obstacle is the destruction of infrastructure (Sadeghi & Ahmadi, 2008; Eide, 2010; Reinhardt et al, 2011; Gosney et al, 2013; Kimuli Balikuddembe, Zeng & Chen, 2020). Following the 2005 earthquake in Pakistan, there was a slow rebuilding of infrastructure, such as roads, electricity networks, and water and sanitation systems (Chishtie et al, 2019). As a result, most individuals with spinal cord injuries and their families involved in the CBR programme had to rebuild their houses in rugged, hilly settlements (Chishtie et al, 2019). In another case, after the 2015 earthquake in Nepal, damage to rural infrastructure limited local relief groups' ability to deliver aid for days and even weeks following the earthquake (Sheppard & Landry, 2016). In a further instance, community infrastructure can

be weakened by prolonged economic turmoil and violent conflict (Torjesen, 2001). When considering the reintegration of individuals into their communities after the earthquake, many buildings were inaccessible to those with mobility aids or wheelchairs (Sheppard & Landry, 2016).

Stigma - Stigma against persons with disabilities was also a common barrier across different settings. The key objective of the case study of Wee (2010) was to explore the factors that impact the ability of refugee participants with a disability to engage in CBR efforts. The main barriers identified were discrimination and stigma (Wee, 2010). In a refugee camp in Kenya, persons with disabilities experienced verbal and physical abuse, difficulty in obtaining healthcare services, and a lack of appreciation of the potential of those with disabilities to contribute to the refugee community (Wee, 2010).

Stigma and prejudice faced by persons with disabilities impact access to support during crises, especially in conflict and post-conflict settings (Jeong et al, 2016). In Kosovo, where many have suffered from armed conflict, there was reportedly stigma associated with disability; although persons with disabilities were well cared for, they were often kept out of sight and unable to integrate into society (Bailey, 2003). Schnabel (2013) described that the stigmatisation of persons with disabilities in Afghanistan is one of the main obstacles that need to be overcome for community integration to be successful.

Recommendations

Some of the articles in this scoping review discussed recommendations for future implementation of CBR programmes (Bailey, 2003; Becker, 2006; Math et al, 2008; Wee, 2010; Amatya et al, 2020; Gruner et al, 2020).

In areas of armed conflict in South-eastern Europe (e.g., Kosovo, Bosnia and Herzegovina, and Albania), Bailey (2003) recommends the following, among many others, concerning landmine victim assistance: improving and upgrading facilities for rehabilitation and psychosocial support; creating opportunities for employment and income generation; capacity building and on-going training of healthcare practitioners; raising awareness on the rights and needs of persons with disabilities; and, supporting local NGOs and agencies to ensure the sustainability of programmes. Furthermore, following a workshop on victim assistance hosted by the International Trust Fund for Demining and Mine Victims Assistance in July 2002, one of the key recommendations was to promote communication among

all actors involved in mine victim assistance (Bailey, 2003). These actors include the relevant government ministries, NGOs, international agencies, donors, and landmine survivors. As Bailey (2003) mentions, cooperation will benefit mine survivors and all persons with disabilities in the region. There should be programmes for children and adolescents who survive landmine injuries, to help them recover.

There were several suggestions regarding CBR and mass displacement. For example, Wee (2010) recommends that there must be adequate organisational support for persons with disabilities within refugee camps. In the refugee camp, there was a clear social hierarchy that was observed: officials in the camps who worked for NGOs were at the top of the hierarchy; next were Somali religious leaders, elected community representatives, and successful Somali businesspersons; afterwards, it was refugees with compensable duties, such as health workers and teachers, followed by unemployed able-bodied refugees; and last came persons with disabilities who had mental conditions (Wee, 2010). Wee (2010) recommends that empowerment strategies be used to improve societal attitudes towards persons with disabilities and promote their participation in community decision-making.

Becker (2006) recommends a “train the trainer” model, which requires a 3-day experiential training programme in psychosocial care for NGO workers, teachers, and local healthcare providers to offer basic mental health to people affected by disasters. This training format was developed by the National Institute of Mental Health and Neurosciences teams in India, where those involved in the training were taught to recognise normal reactions to the tsunami disaster, such as initial shock, disbelief, panic, and hyper-vigilance to the possibility of a second tsunami wave (Becker, 2006). They were also taught to identify those with severe reactions, including despair, guilt, and recurrent flashbacks (Becker, 2006).

Task-shifting practices, which entail shifting tasks from more- to less-highly trained individuals, can be used in situations with a shortage of skilled rehabilitation personnel (Amatya et al, 2020; Gruner et al, 2020). This practice can help expand the healthcare workforce through skill training of non-medical healthcare professionals, to enable more efficient use of the available human resources (Amatya et al, 2020; Gruner et al, 2020).

Amatya et al. (2020) propose the “three-tier approach” as a model for the International Society of Physical Rehabilitation Medicine when dealing with future

natural disasters, to help coordinate and deliver comprehensive rehabilitation assistance with the WHO and other relevant organisations. The proposed Disaster Rehabilitation Response Plan (DRRP) is as follows: tier 1, immediate disaster response at a national/international level; tier 2, organisation and deployment of rehabilitation personnel; and tier 3, rehabilitation management of disaster survivors and community reintegration (Amatya et al, 2020). The DRRP also recommends a formal policy of rehabilitation-inclusive disaster management, coordination of rehabilitation EMTs and their requirements for deployment, advocacy and training, and research and evaluation (Amatya et al, 2020).

Math et al. (2008) explain that concerning CBR, medical and professional rehabilitation services, occupational therapy, physiotherapy, and psychological support should be provided to natural disaster victims as early as possible. Furthermore, it is important to use the existing resources in the community to help empower their engagement following a disaster (Math et al, 2008). Other examples of community-based interventions for mental health following a natural disaster include art therapy, storytelling, structuring of days, engaging in activities, and educating parents and teachers to help in the recovery of children and adolescents (Math et al, 2008). These interventions can be effective for psychosocial rehabilitation of individuals affected by natural disasters (Math et al, 2008).

DISCUSSION

Lack of CBR Research in Armed Conflict, Natural Disaster, and Mass Displacement Settings

This scoping review included 31 articles published from 2000 to 2021, focusing on CBR in settings of armed conflict, natural disaster and mass displacement in low- or middle-income countries. Many articles have focused on rehabilitation in some of the settings mentioned above, but not specifically on CBR. For example, Redmond and Li (2011) studied the immediate medical response after the Sichuan earthquake in 2008. The thesis of Kling (2014) reviewed humanitarian responses after the earthquakes in Pakistan, Haiti and Nepal, including the rehabilitation phases for orthopaedic injuries, but did not refer to CBR. Li et al. (2018) performed a systematic review of physical therapy clients, post-earthquake in China, Haiti, Pakistan and Nepal, alongside other countries, without including CBR. Despite these publications studying rehabilitation in similar settings as the current study, there remains a lack of research on long-term rehabilitation and CBR. Other

articles have focused on CBR, but not in the settings of armed conflict, natural disaster, or mass displacement. For instance, Lukersmith et al. (2013) completed a literature review for monitoring and evaluating CBR programmes. Although this review focused on low- or middle-income countries, targeting children and adults, it did not focus specifically on CBR in the aforementioned settings. Similarly, research by Turmusani, Vreede and Wirz (2002) focused on CBR in developing countries but not specifically in settings of armed conflict, natural disaster, or mass displacement. Based on the search conducted and the timeframe used, the current review is the first to focus on CBR in settings of armed conflict, natural disaster and mass displacement.

Interaction of Barriers in CBR Implementation

This review offers insight into how CBR programmes are carried out in crisis settings and the barriers affecting the implementation of CBR programmes. Awareness of the most common barriers to implementation can help support efforts to develop effective and sustainable CBR programmes. Stakeholders will be supported to anticipate and attempt to mitigate potential barriers.

Despite the efforts of CBR programmes and international initiatives to overcome specific coordination problems, implementation barriers raise questions about the factors that contribute to this situation. These gaps could be seen as the result of interactions between different barriers during the emergency response process. Referring to the WHO management cycle (Khasnabis et al, 2010), the situation analysis could be challenged by the lack of adequate documentation decreasing the ability to share information with the appropriate stakeholders. Furthermore, concerning the planning and implementation phases (Khasnabis et al, 2010), cooperation with local governments could be an issue due to the lack of prioritisation of rehabilitation services in armed conflict, natural disaster, and mass displacement settings. Fewer resources would then be available locally, and the coordination between the acute, post-acute, and long-term phases of rehabilitation would be difficult to manage (Gosney et al, 2011).

Management Cycle (Khasnabis et al, 2010)

Persons with disabilities' participation in the implementation of CBR programmes, and equality and non-discrimination are two of the main principles of the WHO disability-inclusive emergency risk management guidelines (WHO, 2013). However, this review found that discrimination and stigma for persons

with disabilities were common problems across many settings, reducing their participation and agency regarding their own rehabilitation (Wee, 2010; Howard et al, 2012).

Need for Better Training and Community Involvement

The review also highlights the need to improve rehabilitation professionals' training in humanitarian contexts and increase awareness regarding the importance of their roles in these settings. One example that shows the lack of training is the World Confederation for Physical Therapy (WCPT) report in 2016. No global guidelines existed concerning physical therapist training for emergency responses (WCPT, 2016). It is essential to realise that specific disaster training will vary significantly depending on the setting, and trainers should consider the national, regional and individual levels (WCPT, 2016). According to Burkle et al. (2013), humanitarian healthcare professionals should share specific skill competencies related to their degrees, as well as core humanitarian competencies such as "operating safely and securely in high risk environments" and "leadership in humanitarian response", among others (Burkle et al, 2013). Incorporating those competencies as part of every healthcare professional's training would prepare them to intervene locally or globally in situations with urgent rehabilitation needs.

Moreover, it is important to consider that CBR services are mainly delivered by people without formal training (Seijas et al, 2018). The importance of training community workers should also be emphasised since community involvement increases the effectiveness of CBR programmes and promotes the continuum of humanitarian aid.

The articles included in this review also demonstrate the importance of designing CBR programmes in humanitarian settings with strong community involvement. A sense of insecurity and fear could lead to limited engagement with rehabilitation interventions and community participation (Gruner et al, 2020). A study from Burgess and Fonseca (2020), on mass-displaced Colombians in their own country, parallels the results of the present study. The population was living in ongoing distress, which limited their ability to access health services. One significant result was that solidarity within the population promoted empowerment in response to the stigma they were living with (Burgess & Fonseca, 2020). Community involvement may also be facilitated by including local community or spiritual leaders whom local and international NGOs should contact to better understand

cultural practices, needs and healing methods. Programmes that unite the community or families should be encouraged as they promote safe spaces for survivors to express themselves.

The current review shows that delivering CBR services in armed conflict, natural disaster, and mass displacement settings has particular challenges inherent to those settings, but that facilitators also exist to overcome them. Emergency responses can be chaotic, especially if a disaster management plan is not in place (WCPT, 2016). Thus, it will be even more challenging for the local authorities and other stakeholders to prioritise rehabilitation services, especially for individuals with a disability.

Limitations

One limitation of this scoping review is that only English-language sources were included due to the language skills of the researchers. It is unlikely that all the relevant literature is available in English, considering the global nature of this topic. A second limitation of the review was the exclusion of grey literature sources, such as NGO or government reports and policy statements, which likely would have led to a wider set of sources regarding CBR in crisis settings.

Suggestions for Future Research

This review suggests several important lines of inquiry for future research. Further research exploring the perceptions of persons with disabilities about CBR programmes in crisis settings would provide important insights into this topic. Similarly, there are few reports of how rehabilitation workers perceive their roles in CBR in armed conflict, natural disaster, or mass displacement settings. Also, more research is needed to understand the difficulties local and international NGOs face during the creation and implementation of CBR programmes, including collaborations between international and local NGOs and governments. This research will provide insight into considerations of sustainability and partnerships, including potential handovers of programmes after the emergency abates. It can also help build a more robust framework that NGOs can use to ensure continuity if they cease to work in the affected areas. Lastly, stigma associated with mental health and persons with disabilities is one of the main concerns for CBR in humanitarian contexts. Additional research is needed to address these issues and develop strategies or policies that NGOs and government agencies can use to help victims of discrimination.

CONCLUSION

CBR makes important contributions on a global scale, as it works to address the needs of persons with disabilities in a holistic and participatory manner. CBR programmes are especially needed in humanitarian crises because these settings can significantly impact persons with disabilities regarding their health, and social and economic well-being. This review provides insights into facilitators and barriers to implementing CBR programmes in crisis settings. The review can provide insights for CBR stakeholders such as community leaders, health and community workers, local governments, NGOs, disability groups, policymakers and political leaders involved in or developing CBR programmes for humanitarian contexts.

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The authors declare that they have no competing interests.

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Representation of Acquired Disabilities in Australian Research, Policy, and Practice: a Scoping Review

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ABSTRACT

Purpose: Emerging data shows that Australia has a significantly higher number of persons who acquired a disability after birth than persons with congenital disabilities. Little is known about the impact of acquired disabilities on employment outcomes to guide employers, disability service providers and policymakers. This scoping review outlines the gaps in knowledge about the impact of acquired disabilities on employment participation and discusses the conflicting positions of disability models.

Method: A review was conducted of academic and grey literature on disability employment research and policy, published between 1990 and 2021. These were synthesised to analyse the representation of acquired disabilities in research and policy.

Results: It was found that the term “acquired disabilities” is not clearly identified and defined in the literature and the application of terms of reference for disability vary between disability peak bodies and service delivery organisations.

Conclusion: Future research on disability studies needs to capture the definition and identification of acquired disabilities and how they impact on employment outcomes, to foster a unified definition of disability and to devise a refined model of disability that would guide research, policy and practice.

Key words: acquired disability, disability, disability employment, disability models, employment participation, Australia

INTRODUCTION

The impact of acquired disabilities on employment outcomes has not been studied adequately in Australia. Although chronic illness and injury are known

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underlying causal factors of disability according to the Australian Bureau of Statistics (ABS, 2018), very little is known about the resultant disabilities. The boundary between chronic illness and disability has not been clarified, but the terms 'chronic medical conditions', 'impairment', and 'disability' have been used interchangeably in employment policy and practice. This interchangeable use of terms is evident in the official disability employment guidelines issued by the Australian Government's Department of Social Services (DSS, 2019). Moreover, the identification and definition of 'acquired disabilities' has not been formalised.

The prevalence of acquired disability within the working age group (15-64 years old) increases with age (ABS, 2018, 2019, 2020). It is reported that in Australia around 80% of people living with a disability acquired it after birth (ABS, 2018). Additionally, 50% of Australians with a disability also have a coexisting or secondary chronic condition (ABS, 2018). Despite the statistics, there is little evidence of research on the characteristics of acquired disabilities and how they impact on the individual's ability to work.

This scoping review of relevant academic and grey literature on Australian disability employment policy and employment outcomes of people with an acquired disability seeks to identify and analyse the knowledge and gaps in the literature about the impact of acquired disabilities on employment outcomes and how they are represented in research, policy, and practice. It identifies that acquired disabilities are not represented adequately in research, employment policy, and the workplace practices in Australia, and there is very little to guide employers on the impact of acquired disabilities on employment.

Objective

The review was guided by the following overarching question:

How are the factors that enable or limit people with acquired disabilities to gain and retain employment in Australia represented in research, policy, and practice?

The review assessed the representation of acquired disability in research, policy, and practice, and consequently, assessed the impact of acquired disabilities on employment outcomes. The three aims were to:

1. Report what the literature says about acquired disabilities and employment outcomes within Australia.
2. Extract the evidence of acquired disabilities in research, policy, and practice.

3. Synthesise the results and analyse the gaps.

METHOD

Study Design

The purpose of the scoping review is to provide a rigorous synthesis of the evidence on acquired disabilities (Levac et al, 2010), to identify research gaps (Arksey & O'Malley, 2005), and to provide a descriptive overview of the literature (Levac et al, 2010; Peters et al, 2015).

The review was guided by the Population, Concept, Context (PCC) framework (Arksey & O'Malley, 2005). The PCC framework determined the keywords, subject, and index terms used in the search criteria of the literature selected for this review. The target population (P) for this review included people with acquired disabilities within the Australian working age group of 15-64 years. The context (C) of this review lies within the framework of research, policy, and practice. The core concept (C) of this review is the identification, definition, and the conceptualisation of acquired disabilities in research, policy, and practice.

Databases Search and Selection of Scoping Reviews

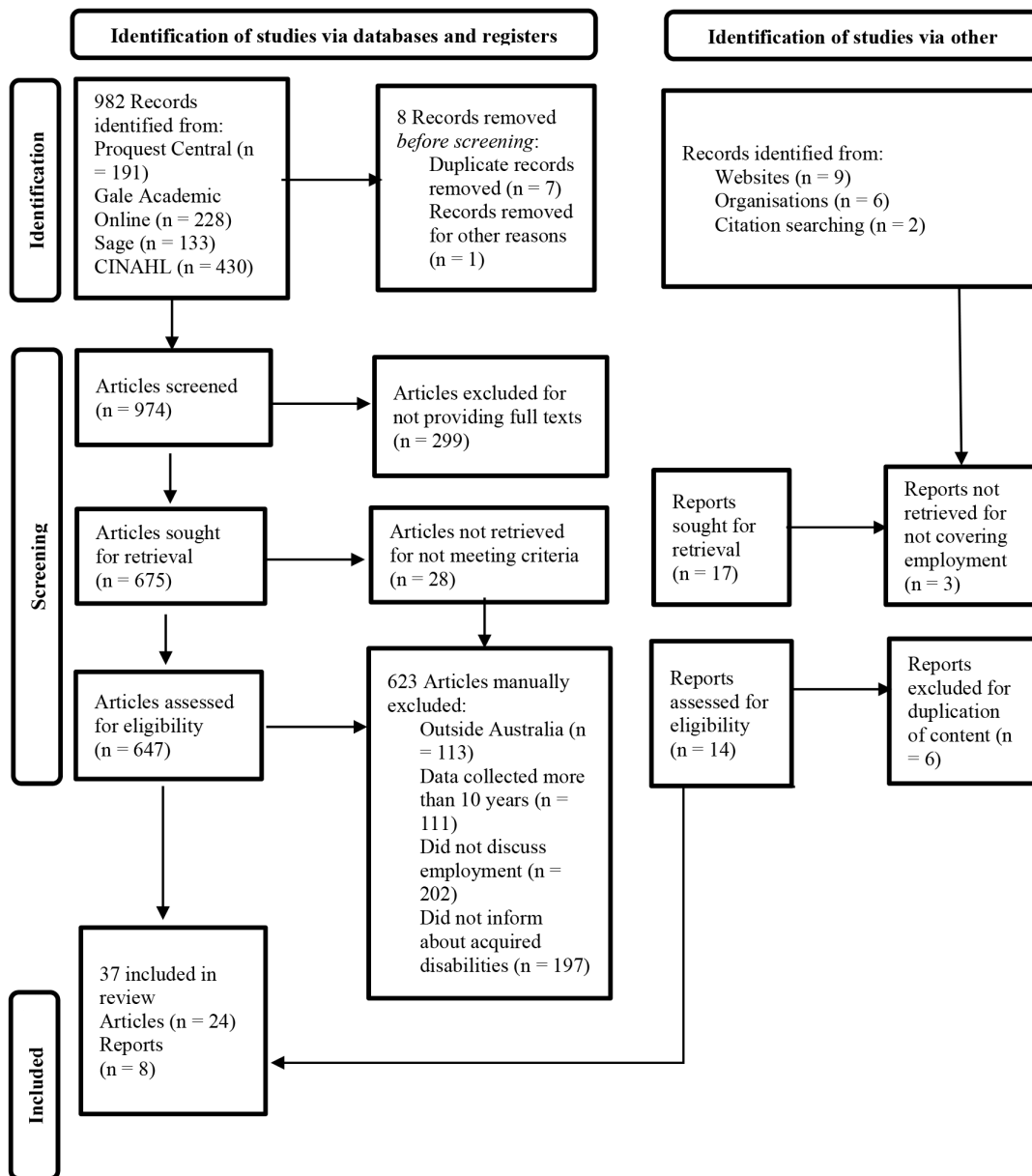
An initial search was conducted on the Proquest Central database in May 2022 to extract keywords within titles, abstracts, and index terms. Following the outcomes of the initial search, a second search was conducted in June 2022. This involved all reviewers applying the keywords across four databases independently: CINAHL, Gale Academic Online, SAGE Journals, and Proquest Central. The databases were selected as they contained public health or social sciences in their description.

Inclusion criteria:

The search was limited to publications from 1990 to 2022. The year 1990 was chosen as the starting point as, arguably, this is when current disability employment legislation and frameworks took shape against the background of the social model of disability (Oliver, 1990; Oliver & Barnes, 1998; Barnes & Mercer, 2005; Shakespeare & Watson, 2010).

Figure 1 displays the PRISMA search pathway used in the selection of the literature.

Figure 1: Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) flow diagram



Source: (Page et al., 2021)

Only publications in English were selected. The Boolean operators were applied against search terms, subjects, and keywords. Terms were searched using either

the exact phrase or abridged terms as follows: Disab* OR impair* OR “acquired disab*” AND employment AND Australia* AND “model* of disability”. Irrelevant and duplicate publications were removed manually by the reviewers collectively. Only 24 articles were included in the review and imported into Endnote.

A further manual hand search on grey literature investigating Australian public health, disability employment, and relevant peak body websites was conducted. Initially, 17 reports were selected, but only 13 contained relevant data/information on disability employment outcomes. These were included in the review.

RESULTS

A total of 37 publications were analysed for this review. These included 24 peer-reviewed articles and 13 reports from Government and Australian disability peak body websites. Of the 13 reports, 5 used the national data mostly derived from the Australian Bureau of Statistics (ABS). These included the Disability, Ageing and Carers report (ABS, 2018), the People with Disabilities report (ABS, 2019), the Labour Force report (ABS, 2020), the Australian Federation of Disability Organisations (AFDO, 2019), and the Australian Institute of Health and Welfare (AIHW, 2022).

Two reports were performance reviews of the Disability Employment Services programme. These were the Australian National Audit Office (ANAO, 2020), and the Taylor Fry report (Fry, 2018 #159). Another report was a statistical report of Disability Employment Services (DES) participants by the National Ethnic Disability Alliance (NEDA, 2014). The remaining four were either policy or the Australian Government service delivery guidelines from the Department of Employment (DoE, 2018) and the Department of Social Services (DSS, 2019, 2021a, 2021b).

The 24 peer-reviewed articles contained 6 longitudinal studies (Hogan et al, 2012; Milner et al, 2014; Schofield et al, 2014; Aitken et al, 2017; Cregan et al, 2017; Milner et al, 2020), 3 literature reviews (Athanasou, 2003; Contreras et al, 2012; Bloom et al, 2019), 2 frontline DES staff surveys (Considine et al, 2011; Considine et al, 2020), 4 qualitative studies (De Jonge et al, 2001; Soldatic, 2017; Soldatic, 2018; Devine et al, 2019), 1 quantitative study (Schönberger et al, 2011), 3 mixed method studies (Thornton & Marston, 2009; Prescott et al, 2019; Devine et al, 2020), 3 programme evaluations of DES and NDIS initiatives (Fowkes, 2011; Reddihough et al, 2016; Miller & Hayward, 2017), a case study and a conference

paper (Hemphill & Kulik, 2016).

Four distinct areas of focus emerged from the review. These were as follows:

1. Definition and identification of acquired disability,
2. Relevant disability employment policies in Australia,
3. Australian disability employment practice and employment outcomes,
4. Discussion of the gaps in the literature.

Author/ Year	Publication Type	Data type	Relevance
ABS. 2018	Census Report	National data	Australian statistics relevant to disability
ABS. 2020	Census Report	National data	Statistics on the Australian labour force
AFDO. 2019	Disability peak body report	Disability peak bodies, DES, ABS data	Disability Employment Services
AIHW. 2020.	Disability peak body report	ABS data	Disability policy and practice
Aitkens et al. 2017	Peer reviewed article	Longitudinal study (HILDA survey)	Long-term health conditions and disabilities
ANAO. 2020	Audit report	DES performance review	Disability Employment Services
Athanasou J. E. 2003	Peer reviewed article	Review of literature	Return-to-work rates following acquired brain injury
Bloom et al. 2019	Peer reviewed article	Systematic Review	Return-to-work rates following a spinal cord injury
Considine et al. 2011	Peer reviewed article	DES front line surveys	Disability Employment Services
Considine et al. 2020	Peer reviewed article	DES front line surveys	Disability Employment Services
Author/ Year	Publication Type	Data type	Relevance
Considine et al. 2021	Discussion Paper	N/A	New DES model
Conteras et al. 2012	Peer reviewed article	Review of literature	Disability Employment Services
Cregan et al. 2017	Peer reviewed article	Longitudinal study (ABS survey)	Impact of restrictive impairments on workplace participation
De Jonge et al. 2001	Peer reviewed article	Qualitative inquiry on people with disabilities requiring assistive technology	Return-to-work strategies
Devine et al. 2019	Peer reviewed article	Qualitative inquiry on people impacted by psychosocial factors	Disability Employment Services
Devine et al. 2020	Peer reviewed article	Embedded mixed methods	Disability Employment Services
DoE. 2018	Government Outcomes Report	DES data	Disability Employment Services
DSS. 2019	Government Disability Demography report	National data	Disability Employment Services
DSS. 2021a	Social policy guideline	N/A	Guide to disability assessments (ESAt/JCA)
Author/ Year	Publication Type	Data type	Relevance
DSS. 2021b	Policy review	N/A	Review of the ESAt assessment
Fowkes, L. 2011	Book	Program evaluation	Disability Employment Services

Fry, Taylor. 2018	Review report	Technical review on DES performance measures	Disability Employment Services
Hemphill and Kulik, 2016	Peer reviewed article	Case study on employers' attitude towards disability	Disability employment participation
Hogan et al. 2012	Peer reviewed article	Longitudinal study (ABS)	Disability employment participation
Miller and Hayward 2017	Peer reviewed article	Review of the NDIS program	Disability employment policy
Milner et al. 2014	Peer reviewed article	Longitudinal study (HILDA)	Disability employment participation
Milner et al. 2020	Peer reviewed article	Longitudinal study (HILDA)	Disability employment participation
NEDA. 2014	Disability peak body report	Focus Groups	Disability Employment Services
OECD. 2010	International report	International data including Australia	Disability best practise
Prescott et al. 2019	Peer reviewed article	Mixed methods	Return-to-work – self-awareness after ABI
Reddihough et al. 2016	Peer reviewed article	Review of the NDIS program	Disability employment policy
Author/ Year	Publication Type	Data type	Relevance
Schofield et al. 2014	Peer reviewed article	Longitudinal study (ABS)	Return-to-work strategies for people with arthritis
Schönberger et al. 2011	Peer reviewed article	Quantitative study	Return-to-work strategies for people with TBI
Soldatic et al. 2018	Peer reviewed article	Qualitative inquiry	Impact of policy reforms on income for ATSI populations
Soldatic, K. 2017	Peer reviewed article	Narrative in-depth interviews	Impact of policy reforms on income for ATSI populations
Thornton and Marston, 2009	Peer reviewed article	Observation and semi-structured interviews	Disability Employment Services
WHO. 2014	International report	N/A	ICF framework

Definition and Identification of 'Acquired Disability'

i. The definition of 'acquired disabilities'

There is no clear and unified definition of 'acquired disabilities' in the literature. Eight reports on Australian disability statistics and performance reviews (NEDA, 2014; ABS, 2018; DoE, 2018; Fry, 2018; AFDO, 2019; DSS, 2019; ANAO, 2020; AIHW, 2022) were analysed for their definition and/or identification of acquired disabilities. Only one report defined 'acquired disability' as a disability that has developed during the person's lifetime as a result of an accident or illness rather than a disability the person was born with (ABS, 2018).

Notably, the representation of acquired disabilities by peak bodies is absent in the reports. As noted in the AFDO report (2019), most acquired disability categories

are not represented by peak bodies or advocacy agencies. As a result, individuals with acquired disabilities are deprived of support in employment and other platforms.

Of the 24 peer-reviewed articles, 8 provided a definition or described the characteristics of acquired disabilities (Athanasou, 2003; Schönberger et al, 2011; Milner et al, 2014; Schofield et al, 2014; Aitken et al, 2017; Soldatic et al, 2017; Bloom et al, 2019; Prescott et al, 2019). Only one included descriptions of acquired disabilities in the definition of disability (Milner et al, 2014). Two included a description that aligns with the characteristics of acquired disabilities as prescribed by the ABS (2018) and International Classification of Functioning, Disability and Health – ICF (WHO, 2014). However, the descriptions did not provide a distinction between acquired disabilities and the underlying medical conditions (Aitken et al, 2017; Soldatic, 2018).

ii. The identification of ‘acquired disabilities’

Three of the reports that were reviewed indicate that the identification of disability varies depending on the context and type of service under discussion (ABS, 2018; AIHW, 2019; DSS, 2019). For example, the identification of disability for the purpose of receiving welfare varies between the wider categorisation used in the application for Disability Support Pension (DSP) and National Disability Insurance Schemes (NDIS) that only considers certain categories of functional capacity (DSS, 2019). Two other reports point out that the lack of a unified categorisation of disability makes it difficult to have a shared language that is less confusing to employers and the community (AFDO, 2019; AIHW, 2022).

Three peer-reviewed articles highlighted chronic health conditions as disabling factors without directly associating the conditions with a disability (Athanasou, 2003; Bloom et al, 2019; Prescott et al, 2019). Lastly, 2 peer-reviewed articles posited chronic health conditions as causal factors of acquired disabilities (Schönberger et al, 2011; Schofield et al, 2014). The literature does not put a clear boundary around chronic health conditions and a disability, making it difficult to tell where the illness ends, and disability begins.

In both the reports and articles, words such as ‘impairment’, ‘activity limitation’, and ‘participation restriction’ were used interchangeably with ‘disability’ (Contreras et al, 2012; WHO, 2014; ABS, 2018; DoE, 2018; Prescott et al, 2019; ANAO, 2020; Devine et al, 2020; DSS, 2019, 2021a, 2021b). Additionally,

expressions such as ‘people living with a disability, persons with a disability’ and ‘disabled persons’ were used interchangeably in different contexts to refer to the same cohort (Thornton & Marston, 2009; Milner et al, 2014; Cregan et al, 2017; Devine et al, 2020; Milner et al, 2020; AIHW, 2022).

Three reports applied the term ‘disability’ in different contexts (AFDO, 2019; DSS, 2019; AIHW, 2022). There were some notable variations in the applications between the National Disability Insurance Scheme (NDIS) and the Disability Employment Services (AFDO, 2019; DSS, 2019; Zyphur & Pierides, 2019; AIHW, 2022); and between the Australian Federation of Disability Organisations (AFDO, 2019) and the National Ethnic Disability Alliance (NEDA, 2014). For instance, the DES application includes chronic health conditions and injuries, whereas NDIS only includes the narrower population of traditional visible disability cohorts (AFDO, 2019; DSS, 2019; AIHW, 2022). These gaps in the application of the term ‘disability’ and the identification criteria used may make one individual eligible for a Disability Support Pension under the social welfare scheme, but not eligible for the NDIS and vice versa (Milner et al, 2014; Devine et al, 2020; Milner et al, 2020; AIHW, 2022).

Relevant disability employment policies in Australia

i. Economic participation and social inclusion

Fourteen publications on Australian disability employment discussed policy in terms of economic participation and/or social inclusion, focusing mostly on the relationship between participation in employment and access to social welfare (De Jonge et al, 2001; Athanasou, 2003; Considine et al, 2011; Fowkes, 2011; Hogan et al, 2012; WHO, 2014; Reddihough et al, 2016; Aitken et al, 2017; Cregan et al, 2017; Soldatic et al, 2017; Soldatic, 2018; ABS, 2020; Considine et al, 2020; DSS, 2021b; AIHW, 2022). Four reports define the Disability Support Pension as an income support payment for individuals aged between 16 and 64 years who have been assessed for a reduced work capacity of below 15 hours a week for, at least, the next two years due to a disability (Soldatic et al, 2017; Soldatic, 2018; DSS, 2019; AIHW, 2022).

However, the Department of Social Services reports that those in receipt of the disability pension who return to the labour force are likely to work fulltime hours, and those initially assessed to be fit to work end up applying for Disability Support Pension (DSS, 2019). It is reported that individuals with a disability

assessed to qualify for the Jobseeker Payments (JSP) increased from 26% in 2014 to 42% in 2019 (Soldatic et al, 2017; Soldatic, 2018; AIHW, 2022). JSP is a means-based income for individuals assessed for a work capacity of 30 hours and under, but not below 15 hours a week (AIHW, 2022).

ii. Vocational rehabilitation and the return-to-work initiative

Three articles discussed disability within the framework of return-to-work strategies following chronic illness or injury without referencing the disability associated with the condition (Athanasou, 2003; Bloom et al, 2019; Prescott et al, 2019). For instance, Athanasou (2003) discussed the recovery and return-to-work of people with an acquired brain injury without referencing the resultant disability even after the condition lasted for over 12 months. The pattern of not attaching a disability to chronic illness that is likely to be permanent is evident in other studies (Bloom et al, 2019; Prescott et al, 2019).

Five publications discussed the complexity of the relationship between a chronic illness and a disability, especially when the disability is invisible or does not fit in the traditional disability categories (WHO, 2014; Aitken et al, 2017; ABS, 2018, 2019; AIHW, 2022). According to the Australian Institute of Health and Welfare (AIHW, 2022) this relationship is dual - that individuals with a chronic illness are more likely to develop a disability, and that those with a disability are more likely to develop chronic illness. This view is also held by Aitken et al (2017) who examined the impact of acquired disabilities on mental health.

However, 2 reports suggest that the above assumption needs to be viewed alongside the claims of the ICF model (WHO, 2014; AIHW, 2022). According to the ICF, not every chronic illness becomes a disability, and the same chronic illness that causes a disability may evolve into other forms of disability (WHO, 2014). Contrary to this, the AIHW (2022) report argued that it should not be assumed that disability is the causal factor of a chronic illness or vice versa. According to the AIHW (2022) report, the causal factor of 21% of acquired disabilities could not be identified, while only 15% are a consequence of a chronic illness and 12% arise from injuries. The rest are attributed to other factors including mental illness, multiple underlying conditions, and ageing. Following this, the review sought to understand employment strategies for people with acquired disabilities that are captured in policy.

iii. The disability model used in Australian policy

Only 3 of the studies discussed disability policy and the identification of acquired disability in line with a disability model (WHO, 2014; Aitken et al, 2017; AIHW, 2022). In Australia, the identification of disability is based on the International Classification of Functioning, Disability and Health (WHO, 2014; Aitken et al, 2017; AIHW, 2022). Within this model, disability is defined as impairments of body function or structure, activity limitations or participation restrictions (AIWH, 2022).

According to Aitken et al (2017) and the World Health Organisation (WHO, 2014), the ICF model employs a biopsychosocial approach and considers socio-environmental, socio-demographic, and behavioural factors of disability as well as the interaction between the individual with the disability and the environment. The model integrates both the biomedical limitations and psychosocial factors (WHO, 2014). Therefore, disability is the result of the interaction between health conditions, personal attributes, and environmental factors (Aitken et al, 2017). This definition suggests that access to social support has a direct impact on impairments, activity limitations and participation restriction.

Five publications position Australian disability employment policy in direct contrast to the claims of the ICF model (Hogan et al, 2012; WHO, 2014; Aitken et al, 2017; Miller & Hayward, 2017; AIHW, 2022). On the one hand, the ICF model seem to posit disability as an unfavourable interaction with the individual's environment (WHO, 2014; Aitken et al, 2017; AIHW, 2022). On the other hand, it is argued that the Australian policy becomes a social barrier by making accessibility to social supports more complicated for some disability types (Hogan et al, 2012; Aitken et al, 2017; Miller & Hayward, 2017).

iv. Workplace relations regulations

Seven publications discussed Australian policy in terms of legislation (Hogan et al, 2012; Reddihough et al, 2016; Soldatic et al, 2017; Soldatic, 2018; DSS, 2019; ABS, 2020; AIHW, 2022). Four of these publications focused on the Disability Discrimination Act (Hogan et al, 2012; Soldatic, 2018; DSS, 2019; AIHW, 2022). According to Hogan et al (2012), this legislation was implemented to enable those with a disability to access the same employment opportunities as those without disability. Access to employment opportunities would then reduce the number of people with a disability accessing the Disability Support Pension (Soldatic et al, 2017; Soldatic, 2018). However, approximately 30% of all social welfare benefit

recipients aged between 16 and 64 years receive Disability Support Pension, with most of them (82%) remaining on it for at least 5 years (AIHW, 2022). Among these, 36% report psychological or psychiatric conditions as their disability (ABS, 2020; AIHW, 2022).

Additionally, some have placed the challenges of return-to-work processes on the cost of workplace modifications, the cost of accommodating people with disability in employment, and a general lack of confidence in government subsidies and support (Fowkes, 2011; Contreras et al, 2012; Hemphill & Kulik, 2016). Others dismiss the emphasis on workplace accommodation citing that statistics show that most people with a disability do not require workplace modifications or supports (AIHW, 2022).

Australian disability employment practice and employment outcomes

A total of 14 publications positioned the goal of moving people with a disability from welfare to sustainable employment on DES and/or the NDIS (Considine et al, 2011; Fowkes, 2011; Contreras et al, 2012; Milner et al, 2014; DoE, 2018; Fry, 2018; AFDO, 2019; Devine et al, 2019; DSS, 2019, 2021a, 2021b; Considine et al, 2020; Milner et al, 2020; Considine et al, 2021). These are discussed below:

i) Disability Employment Services (DES)

Four government reports indicate that the majority of funding is disseminated as service and outcome fees as well as wage subsidies channelled to DES providers (DoE, 2018; DSS, 2019, 2021a, 2021b). Three publications gave a historical account of the disability employment policy from the period when the Australian Government started outsourcing disability employment services to commercial and community organisations and the inception of the DES in 2010 to replace previous programmes (Thornton & Marston, 2009; Devine et al, 2019; DSS, 2019). This outsourcing of services is said to have shifted the role of the Government from provider to purchaser of services (Considine et al, 2011; Considine et al, 2020).

Eleven publications position DES within the broader welfare system (Considine et al, 2011; Milner et al, 2014; NEDA, 2014; Hemphill & Kulik, 2016; Soldatic et al, 2017; DoE, 2018; Soldatic, 2018; AFDO, 2019; Devine et al, 2019; DSS, 2019; Devine et al, 2020). Five of these point out that most of the DES participants are referred into the services as a part of mutual obligations for receiving welfare-

to-work payments (Hemphill & Kulik, 2016; Soldatic et al, 2017; Soldatic, 2018; Devine et al, 2019; Devine et al, 2020). Three articles argued that the welfare-to-work mutual obligations are punitive and lack a focus on rehabilitation (Soldatic et al, 2017; Soldatic, 2018; Devine et al, 2020).

Two publications argued that the services provided by DES were not aligned with the goals of individuals referred to the programme (Milner et al, 2014; Devine et al, 2019). Various factors are identified as contributing to the misalignment. Some suggest that DES frontline staff do not have the right qualifications, attitudes, or skills to assist individuals with a disability to meet their goals (Considine et al, 2011; Contreras et al, 2012; NEDA, 2014; AFDO, 2019; Considine et al, 2020).

However, 6 articles and 2 reports questioned the competence of the current DES model to address the disability gap (Considine et al, 2011; Fowkes, 2011; Contreras et al, 2012; NEDA, 2014; AFDO, 2019; Devine et al, 2019; Considine et al, 2020; Devine et al, 2020). Three discrepancies are highlighted as the causal factors. These are:

The ability of DES consultants to deliver a recovery-oriented programme (NEDA, 2014; Devine et al, 2019; Devine et al, 2020),

The lack of professional qualifications required to become a DES specialist (Considine et al, 2011; AFDO, 2019; Considine et al, 2020), and

The high staff turnover that disrupts continuity of service delivery (AFDO, 2019; Devine et al, 2019).

According to the AFDO reports, only 30% of DES participants remain in employment for more than 26 weeks (AFDO, 2019) and only 13% of those with chronic illnesses reach this milestone (Fry, 2018).

ii) National Disability Insurance Scheme

Five publications call for the reform of DES programmes to give participants total control over who provides services to them and how their funds are managed (Milner et al, 2014; Hemphill & Kulik, 2016; Reddihough et al, 2016; AFDO, 2019; Devine et al, 2020). Two of these cited the NDIS as the ideal model (Hemphill & Kulik, 2016; Reddihough et al, 2016). However, the authors of 2 articles noted that it is too early to measure the effectiveness of the NDIS programme. The NDIS programme was rolled out in 2013 to improve the personal goals of people with disabilities including reducing the disability employment gap by allocating funds

to individuals instead of organisations (Hemphill & Kulik, 2016; Reddihough et al, 2016; Miller & Hayward, 2017; DSS, 2019).

Australia is rated among OECD countries with the lowest participation rates of disability employment participation and the highest rates of disability income and welfare payment (OECD, 2010; Soldatic, 2018). Participation rate is a calculation of people in the labour force against the adult population in the working age groups (ABS, 2018, 2020). According to Cregan et al (2017), there is minimum evidence that disability employment policies are achieving the intended goals of social inclusion.

DISCUSSION

Gaps in the Literature

The publications that were reviewed show gaps in several areas. These gaps were apparent in the lack of a unified definition of acquired disability, the identification of acquired disabilities in policy and practice, and the limited guidance around the impact of acquired disabilities in employment outcomes. The lack of a unified definition has a clear impact on research, policy, and practice in that it blurs the framework and conceptualisation of the phenomenon.

The term 'disability' is applied differently in varying contexts. Notably, the identification of acquired disabilities differs from one article to the next and between reports. This leaves very little to inform and guide employers, service delivery, and policymakers about the impact of acquired disability on employment outcomes.

The Government reports show that the term 'disability' is applied differently for different programmes, and the assessment tools used to reach these conclusions are different. For example, the review has noted that one may be eligible for Disability Support Pension within the DES context, but not eligible for NDIS and vice versa (DSS, 2019, 2021b). These varied categorisations not only make disability service delivery complicated, but also make accessing the services complicated for participants.

The inconsistencies in identification and definition of disability in the Australia context demand an examination of policy, definition and identification of disability, and the application of the adapted ICF framework in disability assessments, its claims and effectiveness in practise. Government reports show

that some individuals who were initially assessed for the Disability Support Pension but decided to return to the workforce, worked fulltime hours (DoE, 2018; DSS, 2019). When viewed in conjunction with Soldatic's (2018) assertion that there has been a fluctuating increase of individuals with a disability who were initially assessed for a work capacity benchmark of at least 15 hours attempting to access the Disability Support Pension, it shows a surprising discrepancy between assessment outcomes and actual resultant participation.

Australian research has mostly utilised data from peak bodies specialising on specific disability types, or from demographics selected from specialised organisations. This is problematic for a variety of reasons. Firstly, most acquired disabilities are not represented by any peak body or disability organisation (AFDO, 2019), thereby resulting in the data not accurately representing the problem on the ground. Secondly, as shown in the ABS (2018) data, Australians tend to experience more than one type of disability as they advance in age, and some of these acquired disabilities can be invisible.

Limitation of this Review

The lack of a unified identification and definition of disability in the literature made it difficult to differentiate acquired disability from the underlying chronic health conditions. In most cases it was impossible to tell from the descriptions whether the literature under review was discussing a disability or a medical condition. In some cases, disability was used synonymously with impairment, chronic illness, and/or injury. As a result, it became a challenge to work out whether the impact was due to the underlying health condition or to the acquired disability – or whether the two should be read as synonyms.

CONCLUSION

Understanding the factors affecting the ability of people with acquired disabilities to obtain or sustain employment appears to be a necessary body of knowledge to close the gap between the participation in employment of those with a disability and those without. Three areas of knowledge are particularly important:

- 1) There is a need for research to understand the relationship between health, impairment and disability.
- 2) There is a need to understand the impact of acquired disabilities on employment outcomes, as well as gaining knowledge to foster guidelines for positive outcomes.

- 3) There is a need to test the application of the ICF model, including its claims and effectiveness in assessing disabilities and guiding policymakers, employers, and communities for improved employment outcomes.

Extant research has not effectively captured the identification and definition of acquired disabilities and the impact on the employment outcomes. Therefore, future research needs to study these factors and how this knowledge might inform disability studies, not only to enhance entry into the workforce for people with a disability, but also to understand how acquired disabilities influence exit from employment. Such research is necessary to foster a unified definition of disability and to devise a refined model of disability that would guide research, policy and practice.

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All material used herein is the original work of the researchers. All cited work was referenced using the APA referencing style.

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CASE STUDY

Implications of a Holistic Rehabilitation Approach following Spinal Cord Injury: A Case Study from India

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ABSTRACT

Purpose: Spinal cord injury causes temporary or permanent changes in spinal cord function. This case report highlights the significance of multidisciplinary rehabilitation team interventions after surgery for spinal cord injury.

Method: The paper examines the case of a 16-year-old girl, diagnosed with spinal cord injury after a traumatic incident four months earlier. The adolescent (client), a 9th grade student from a lower socioeconomic background, presented with weakness in the lower limbs, pressure ulcer, and neuropathic pain. Along with dependency for lower limb activities of daily living, there was severe biopsychosocial impairment. The client's mother had no respite during the entire process of caregiving. On the basis of psychosocial findings, specific customised interventions were administered to the client and her mother, on a daily basis, for one and a half months.

Results: Different scales were used to assess the quality of life (BREF-QoL), illness perception (Brief IPQ) and depression and anxiety (HADS) of the client, both pre and post interventions. A comprehensive tailor made psycho-social interventions were provided during and after the rehabilitation and significant improvement was found. Scales to assess the social and occupational functioning (SOFAS) of the family and perceived family burden also noted positive changes.

Conclusion: Psychiatric social work interventions play a vital role in rehabilitating persons with neurological conditions. Adopting holistic rehabilitation approaches enhances the well-being and quality of life of persons with spinal cord injury and their families.

Key words: spinal cord injury, psychosocial, rehabilitation, India

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INTRODUCTION

Damage to the spinal cord or spinal cord injury causes temporary or permanent changes in spinal cord function. Persons with spinal cord injury and their family members experience enervating physical, social, and vocational consequences post the spinal cord injury (Ahuja et al, 2017). Clinician's goals should be to diminish the negative impact of impairments, promoting full participation in all the life domains and ultimately increasing the well-being of individuals with spinal cord injury (Simpson et al, 2012). The holistic rehabilitation approach post spinal cord injury is an important aspect of treatment, which is demonstrated here with the support of a case study. Access to appropriate care determines the success of the approach (Shroff et al, 2015).

METHOD and RESULTS

Case Description

Ms. T is a 16-year-old girl, studying in the 9th grade in a school in Bangalore city, India. She comes from a lower socioeconomic background. While playing with her friends, she fell from the second floor of her building and was rushed to the emergency care services at a tertiary care centre. The client was diagnosed with traumatic spinal cord injury, and underwent L2 laminectomy decompression surgery. She was subsequently referred to the Department of Neurological Rehabilitation to receive multidisciplinary team interventions as an in-patient. The client presented with weakness in the lower limbs, pressure ulcer, and neuropathic pain. Along with dependency for lower limb ADLs (activities of daily living), there was severe biopsychosocial impairment since the past four months. Specific scales were administered at the time of admission, and the scale scores have been listed in Table 1.

Table 1: List of Scales administered in the Hospital

Scale	Total Score	Score		Purpose	Result
		Pre	Post		
BARTHEL Index	100	30	14	To assess the activities of daily living	Dependent in activities of daily living
American Spinal Cord Injury Association (ASIA)	A	C	D	To assess the impairment and severity	Incomplete motor function is preserved below the neurological level and the majority of key muscles below the neurological level have a muscle grade less than 3

Hospital Anxiety and Depression (HADS)	21	13	2	To assess the depression and anxiety	Borderline
Spinal Cord Injury Independent Measure (spinal cord injury M)	100	42	13	To assess the independency	Dependent

The team referred this particular case to the psychiatric social worker during the client's in-patient stay. Findings of the psychosocial assessment are mentioned in Table 2.

Table 2: Psychosocial Factors involved in the Client's current condition (Stokes, 2011)

Risk Factors	Maintaining Factors	Protective Factors
<p>Individual factors</p> <p>Dependent in lower limb activities of daily living</p> <p>Poor knowledge about spinal cord injury</p> <p>Poor coping skills</p> <p>Borderline anxiety and depression</p> <p>Ruminating and feeling guilty about the traumatic incident</p> <p>Comparing with other spinal cord injury inmates</p> <p>Worrying about academics and future</p> <p>Family factors</p> <p>Poor knowledge about spinal cord injury</p> <p>Health issues of parents</p> <p>Caregiver burden (Client's mother)</p> <p>Financial constraints</p> <p>Unrealistic expectations</p> <p>Poor coping and problem-solving skills</p> <p>Community factors</p> <p>Poor secondary support system</p> <p>Lack of welfare benefits</p> <p>Rumours at school</p> <p>Classroom is on second floor</p>	<p>Individual factors</p> <p>Poor coping skills</p> <p>Family factors</p> <p>Health issues of parents</p> <p>Community factors</p> <p>Rumours at school</p> <p>Classroom is on second floor</p>	<p>Individual factors</p> <p>Enhanced self-esteem</p> <p>Highly motivated</p> <p>Family factors</p> <p>Adequate primary social support system</p> <p>Community factors</p> <p>Adequate tertiary social support (from NIMHANS, Lions Club, iCare Foundation, Satya Sai Baba hospital)</p>

Assessment of family dynamics indicated that family members could not perform culturally expected roles. The father is the nominal and functional leader and the decision-maker of the family; however, the mother was the primary caregiver in the ward. The mother performed multiple roles during the caregiving process.

The family was facing severe economic hardship in meeting caregiving expenses, the cost of medication and other treatments, coupled with inadequate secondary emotional, instrumental¹, and social support. On the basis of the psychosocial findings, specific customised interventions were administered to the client and her mother, on a daily basis, for a period of one and a half months; these are mentioned in Table 3.

Table 3: Psychiatric Social Work Interventions

S. No.	Name of the Intervention	Purpose	Given to / Participated
1	Educating about spinal cord injury	To impart an insight about nature, types, causes, course, management, prognosis	Client & caregiver
2	Supportive psychotherapy	To ventilate and validate the client's feelings	Client & caregiver, separately
3	Activity scheduling	To keep the client engaged and distract from anxiety-provoking thoughts	Client
4	Coping skills	To teach healthy coping strategies	Client & caregiver
5	Problem-solving skills	To teach problem-solving strategies	Client & caregiver
6	Wheelchair Zumba	To enhance mobility and muscle coordination	Client
7	Peer supportive group	To discuss the illness, current concerns, coping strategy, future plans of the peers	Client
8	Recreational group	To relieve stress, enhance psychological well-being, coping skills	Client & caregiver
9	Art therapy	For mindfulness and emotional regulation, increase self-esteem, relieve stress	Client
10	Pre-discharge counselling	To discuss treatment adherence, drug adherence, regular follow-up	Client & caregiver
11	Tele follow-up	To ensure the treatment and drug adherence (not psychiatric drugs), continue supportive work	Client & caregiver
12	Liaising with NGOs i. iCare Foundation ii. Lions Club iii. Satya Sai Baba hospital	i. Reimbursement of the mobility aid and medicine bills amount ii. To donate the wheelchair iii. To undergo cardiac surgery for client's father	Client & caregiver
13	Home visit	To identify the environmental barriers, administer the scales, to assess the client and family needs, concerns, to continue therapy interventions for the client and family	Client & caregiver
14	School visit	To address the rumours in class, conduct awareness programme in client's class, implementation of supportive education concepts, environmental modifications, accessible atmosphere, to discuss with the school management	Client & caregiver

(Note: Social work practice in the mental health setting is called Psychiatric Social Work. In India, trained psychiatric social workers provide their expert services during neurological rehabilitation as neurological disorders have associated psychosocial sequelae. The psychiatric social workers are usually postgraduates

¹ Instrumental support is the support provided to meet the materialistic, financial needs such as, personal and medical care, transportation, and meal preparation etc.

in super specialities with MPhil or PhD degrees, or research scholars.)

A list of the scales administered at the hospital and at the client's home is presented in Table 4.

Table 4: List of Scales administered at the Hospital and at the Client's Home

Scale	Purpose	Score		Inference	
		Pre	Post	Pre	Post
BREF Quality of Life (WHO)	To assess the quality of life of client	31	90	Poor quality of life	Good quality of life
The Brief Illness Perception Questionnaire (Brief IPQ)	To assess the illness perception	67	09	Extremely affected	Mildly affected
Hospital Anxiety and Depression (HADS)	To assess the depression and anxiety of the client	10	02	Borderline	Normal
Participation scale	To assess the participation of the client	72	14	Extreme restriction	Mild restriction
Social and Occupational Functioning Assessment scale (SOFAS)	To assess the social and occupational functioning of the family	29	81	Inability to function	Good functioning
The Perceived Family Burden scale	To assess the family burden	68	11	High burden	No burden

Drawings and filling in Mandala patterns were part of both ward and home-based activity (see Figure 1), while home and school visit pictures are shown in Figures 2 and 3.

Figure 1: Drawing (left) and Mandala picture (right) done by the Client

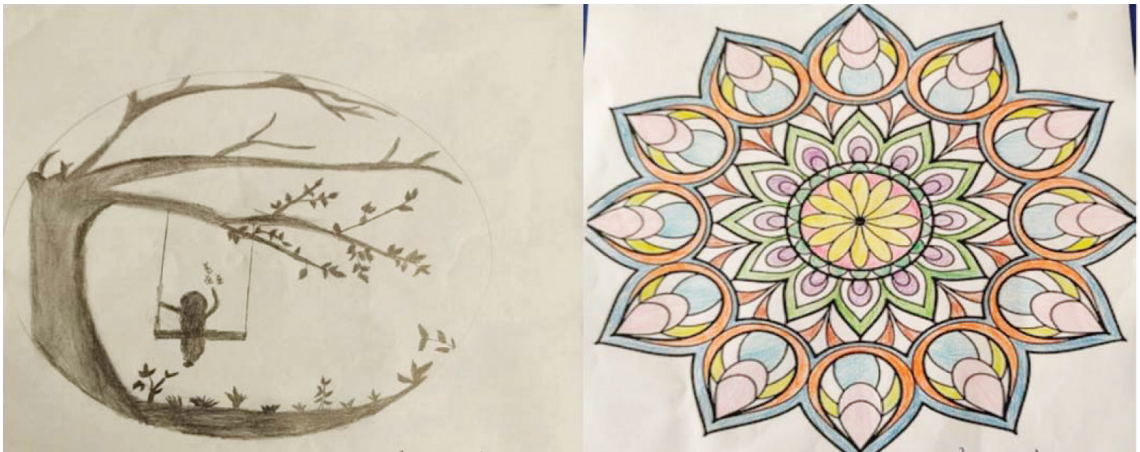


Figure 2: Photos of Home Visit (Client's home - right, and Accident site - left)



Figure 3: Photos of School Visit (Client's school – left, and Classroom – right)



Ethical Considerations

The client and her parents were informed about the publication of this case and gave their consent. Client confidentiality has been ensured.

DISCUSSION

This case highlights the importance of a holistic approach (hospital-based and community care), and the implications of psychotherapy and telerehabilitation. Caregiver burden, burnout, knowledge and attitude of the client and her family, wrong notions and beliefs of the family members, challenges in returning to education and vocation, were the investigative factors in this case. The implication is that the sudden onset of traumatic spinal cord injury and medical complications may have given rise to common psychosocial issues for the client

and her family. Owing to their low socioeconomic status, the client's mother had to perform multiple roles in her daughter's treatment and care, and consequently experienced physical, emotional, and social exhaustion, with no respite during the entire process of caregiving. It is necessary to address the needs of both the clients and their caregivers by the mental health professionals, as unmet needs have a direct relationship with diminished quality of life (Sweet et al, 2014).

The holistic rehabilitation approach (institute-based rehabilitation, outreach-based rehabilitation, and community-based rehabilitation) (Singh et al, 2017) has been adopted in this case. The client was provided with all the required institute-based rehabilitative services like medical treatment, nursing, physiotherapy, occupational therapy, urodynamic, clinical psychologist interventions, and psychiatric social work services during her inpatient stay. The outreach-based rehabilitation approach served to provide home-based therapy services to the client, which was supervised by the family and by the psychiatric social work team over the telephone, i.e., through telerehabilitation.

A community-based rehabilitation approach (home visit and school visit) was adopted to reduce the attitudinal and environmental barriers with the active participation of the family and community members. Singh and his colleagues (2017) have also stressed the importance of a holistic approach for better community reintegration post spinal cord injury. The client's mother reported that people's 'evil eye' might reduce the recovery rate, if she were to send her daughter outside for community participation. The psychiatric social work team educated the client's family about this issue and about the importance of community participation. Research evidence too has suggested that cultural and traditional beliefs act as a barrier in the process of rehabilitation (Olaogun et al, 2010). Various studies across the globe have demonstrated that the implications of different psychosocial interventions are helpful for both the clients and their caregivers; caregiver training programmes have contributed towards successful community integration (Tyagi et al, 2019). Various psychosocial interventions, like enhancing caregiver's coping skills, social support, skills training, access to the community services, and continuity of care, contribute to providing the caregiving services sustainably to persons with spinal cord injury (Jeyathevan et al, 2020).

This case study confirms with other research findings that health care professionals should use psychosocial interventions to rehabilitate persons with spinal cord injury to reduce the psychosocial issues (Deyhoul et al, 2020). Studies have

suggested that implementing family-centred empowerment approaches among caregivers of persons with neurological conditions have resulted in effective outcomes to reduce the burden of care, improve the roles of caregiving persons, and improve the quality of life of the care recipient. It is challenging for persons with spinal cord injury to return to school as it involves enormous support from the community, and financial difficulties would be another risk factor, especially for children in low-income countries (Shem et al, 2011). A recent narrative review suggests that the delivery of psychotherapy and vocational services to the person with spinal cord injury via tele-neurorehabilitation is appropriate (Irgens et al, 2018).

Tele-neurorehabilitation is offered to needy clients who are unable to access healthcare facilities due to long distances, immobility, cost, and/or the non-availability of an expert clinician in their geographical area. Tele-neurorehabilitation services encompass a variety of services such as client consultation, education and training of families and professionals in the area, follow-up of clients, and monitoring of tele-neurorehabilitation services.

The criteria which were taken into consideration to provide tele-neurorehabilitation services to the client were: inability of the caregiver to bring the client to the hospital, burden of the indirect cost of the treatment, and health issues among the parents. Psychiatric social work interventions, by adopting the holistic rehabilitation approach and including other allied multidisciplinary team approaches, have helped both the client and her family to improve their functionality and well-being.

CONCLUSION

It is imperative to understand the various psychosocial issues following spinal cord injury among young persons. Psychiatric social workers address the needs and support persons with spinal cord injury and their caregivers through in-depth psychosocial assessment. This case report highlights the significance of multidisciplinary team interventions. Psychiatric social work interventions play a vital role in rehabilitating persons with neurological conditions as they enhance well-being and quality of life. Adopting the holistic rehabilitation approach will help persons with spinal cord injury and their families. Rehabilitation professionals can consider the significance of looking beyond the symptomatology and incorporate multidisciplinary team interventions in their treatment.

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EXPERIENTIAL ACCOUNT

Incorporating Music Therapy-Informed Techniques into CBR: Experiences from Practice with two Children and their Families in Rural India

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ABSTRACT

Purpose: *This experiential account describes the process and observed impact of including music therapy-informed techniques into community-based rehabilitation for two boys with disabilities in rural India. The aim is to inform other CBR facilitators and grassroots organisations of the potential of including music in CBR.*

Method: *This is reported from the perspective of two experienced CBR programme leaders. While their experiences of integrating music into CBR are narrated, the methods used are reported elsewhere in an accessible format (see in-text for link). The individual cases are part of an international research collaboration between Australian music therapists and Indian CBR facilitators.*

Results: *In the two cases described, music in CBR supported existing physical development goals, and increased motivation and engagement in CBR for the children and their supporting communities.*

Conclusion and Implications: *Online peer-mentoring between music therapists and CBR facilitators can support CBR facilitators to use music in ways that supplement their existing skills. It also offers novel and engaging new ways for them to motivate participation and support development for children with disabilities and their families. CBR facilitators found that they were able to effectively embed music into their CBR work and that doing so enhanced their enjoyment and engagement in CBR.*

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Key words : Music therapy; community-based rehabilitation; intercultural collaboration; online skills sharing; disability; digital health

INTRODUCTION

This experiential account presents two stories of community-based rehabilitation for two boys - 16-year-old Ranjit and 7-year-old Pallav (pseudonyms used to protect participant privacy). Both young people live in a rural area of central India, and both were participants in an intercultural music sharing programme which aimed to incorporate music therapy-informed strategies into home-based CBR for children with disabilities and their families. The programme was part of a practice-based research collaboration between a large Indian healthcare network and an Australian university, conducted between 2018 and 2022, funded by an internal university grant. This research collaboration studied the process and impact of introducing music therapy-informed strategies into CBR in rural India. More project information including video examples can be seen at: https://www.youtube.com/watch?v=OYH_WYegH54

METHOD and RESULTS

Design

These two stories are the experiential accounts of two programme managers from two grassroots disability organisations who were involved in supporting Ranjit's and Pallav's rehabilitation. These programme managers oversaw the music programmes for their organisations and observed first-hand the impact of integrating music into CBR for these young people. Their observations are shared in order to inform CBR facilitators in the field about potential benefits of using music therapy-informed techniques in CBR. Further publications reporting overall findings from this research collaboration are currently pending publication.

Tools

The programme began in 2018 with a 4-week visit to India by an Australian music therapist and 5 music therapy students. They observed and learned about the existing CBR home-based therapy programme in the region, shadowing local Indian counterparts from two grassroots disability organisations. They then developed ideas for how music may be incorporated into the existing CBR

programme. CBR facilitators and coordinators of the grassroots organisations attended training sessions, workshopped ways to use music with children with disabilities as part of their work and gained information about how music can support rehabilitation goals. Music sharing activities such as instrument playing, singing together and listening to familiar music were then incorporated into CBR sessions in the children's homes.

Following the visit, video footage of music-based CBR interactions were sent weekly to the Australian music therapy team via WhatsApp. Observations and ideas were then shared back and forth between Australian music therapists and Indian CBR facilitators over a two-year period. This method of online sharing with external therapy consultants was a pre-established process for CBR work with the participating grassroots organisations and was therefore adopted for music therapy consultation as well.

Alongside the intercultural music sharing programme, an action research project studied the ways that the programme may be helpful or otherwise in this context. The research group was made up of university academics, organisation research coordinators, programme managers of the disability organisations, and CBR facilitators. The disability organisation programme managers who present these experiential accounts were co-researchers from this group and developed these stories with Australian music therapy co-researchers. The writing process began with verbal storytelling that was audio-recorded on Zoom. This was transcribed, then checked and collaboratively edited. The verbal language was edited to written language to provide additional clarity and context, and then re-checked for accuracy by all four authors. Attempts were made to remain as faithful to the original descriptions as possible. In each story, the child is described briefly, followed by a description of how the addition of music was observed to impact the child and their CBR programme, as well as their family and support network.

Music in CBR with Ranjit

Ranjit, a 16-year-old boy, lives with his family of five - his parents, older sister, and grandmother. A class 10 student, he enjoys playing outdoor games and is referred to as a good boy who respects and listens to his CBR facilitators.

Ranjit has had significant physical impairments since childhood. Before the introduction of a therapy programme, he was unable to move his hand or wrist or fingers as they were very bent. He could not straighten his right leg

which was bent upward from the knee. The CBR facilitators introduced him to physiotherapy, but he did not take much interest. They were aware that if they stopped the physiotherapy, Ranjit would not continue with it as there was little family involvement.

The music therapists discussed the benefits of introducing music into the CBR programme.

When therapy through music began and goals were set, Ranjit showed a lot of interest. There was a shift from passive acceptance to active engagement with therapy. The CBR facilitator was not doing the movements alone; Ranjit had begun to cooperate. Sometimes movie songs were played, such as promotional Indian film music, and Ranjit began to take an active role, doing all the stretching, strengthening, pulling, and finger and gripping movements that were prescribed. The CBR facilitators recognised his interest in therapy while playing and listening to music, although he did not express this.

Apart from the youngster, other members of the family and the neighbouring children also became interested in the ongoing therapy. This is described as 'social mobility'. Doing group therapy with the involvement of family members and others yielded many positive results. Whenever the CBR facilitators said, "*Let's do some group music therapy*", other children would come and sit with Ranjit. They formed a group and enjoyed playing alongside him. His parents were also involved. Although the therapist was concentrating on the client, it was observed that family involvement made Ranjit feel, "They are concerned for me; they wish me well". He did not feel alone.

With motivation and the positive feeling of group participation, Ranjit started mingling with family members and other children. His parents were pleased when they saw not only CBR facilitators, but also other people coming and helping their child to play. So, joyful group playing became therapy for Ranjit.

Another element of the music therapy process was that it motivated the family to help Ranjit continue with exercises in the absence of the CBR facilitators. If the facilitators were not able to come, the parents were advised to play any song – from a movie or a famous song - and Ranjit had to do sit-ups or dance for 5 minutes. If he was unable to manage without support, he could hold onto something with his hands. In this way therapy for his legs began with stretching as well as standing movements, in the absence of the CBR workers. Ranjit is now able to stand on both feet for 10 minutes at a time, whereas earlier he used to

stand on only one leg. His balance while walking is also improving slowly.

The CBR facilitators observed that Ranjit was able to shake his wrist after music therapy. He was learning these movements by using drums and shakers. He is now able to move his fingers, and has begun to hold a pen and pencil. Previously, writing was difficult because of painful fingers and inability to flex his fingers and wrist. By continually doing music therapy for stretching and movement for the fingers, Ranjit has gradually begun to write with the affected hand. He is also able to carry and hold small items.

Ranjit has received a lot of encouragement through music therapy. The improvements are apparent and, hopefully, will continue. CBR facilitators have also found that music therapy has made their work much easier, and they have enjoyed administering it.

Music in CBR with Pallav

Pallav, a 7-year-old boy, lives with his mother and two sisters. He has cerebral palsy and multiple disabilities (speech and intellectual disability). Totally dependent on others for help, he was always lying down unless supported to sit up. There was a full-time helper to look after and/or help him to complete his tasks.

Pallav would be taken to a Day Care Centre regularly, and the CBR facilitators would visit him at home to provide therapy. The CBR workers did a case study and made SMART goals for Pallav: to stand with support; to sit without support; to develop his grip to hold objects; and to improve his body movements. Targets were set to improve his sitting position and hand and leg movements. Passive exercise and playful activity to develop skills and grip were offered, but Pallav used to cry while being given therapy or made to do any of the activities.

When the CBR facilitators started to administer physiotherapy along with music, the child would respond for longer periods without crying. Listening to music helped him to forget his pain and continue therapy. He got involved in group activity and began to smile during interactions. Music therapy techniques also helped Pallav to develop his hand movements. When the CBR workers sang, "*Pallav, Pallav, you have to do*", he was happy to hear his name and would smile in response. Playing with the egg shaker, finger cymbals, tambourine, and the ocean drum require a lot of hand movements. The up-and-down motion provided good exercise for his shoulder, while using instruments encouraged Pallav to

do finger exercises that strengthened his grip to hold objects. Now, he is able to stand with support, sit without support, beat the drum, hold shakers, and follow instructions from CBR facilitators.

Through music, the CBR workers were able to give particular exercises, develop Pallav's interest to sit and beat the drum, and to hold and shake the shaker. Pallav was thus motivated to do active, free exercise by himself.

On noticing that Pallav was interested in group music therapy, the CBR facilitators started to involve him in group activities with minimal support. Activities to practice start/stop, slow/fast, mirroring and matching, helped Pallav to understand the rules of group activity. He learned how to take turns and how to imitate others. He enjoyed being part of the group and responded with a smile or loud voice. For example, to learn how to start or to stop, he would be told, "*Pallav, clap your hands*"; then he would clap and follow the leader.

The CBR workers also got family members involved in helping Pallav. Both his sisters cooperated and made time to play music and sing songs so that Pallav's movements, speech development and social interaction improved. They looked after him while their mother was at work and encouraged him, through music, to stand with support and do strengthening exercises.

At each visit the CBR facilitators would greet Pallav by singing, "*Pallav, Namaste Pallav*". The child understood that they were singing for him and would respond with a smile and lots of hand movements. Music (song adaptation) gave him special energy to do actions and follow instructions. Pallav was especially happy to listen to songs that mentioned his name, like "*Namaste Pallav*", "*Pallav ko chalnahai*", poems and so on.

Music supported Pallav to improve his hand movements, grip, balance to stand with support, and to sit without support. He is now able to hold a spoon with minimal support and tries to feed himself. The CBR facilitators are very pleased with his progress. The family members are very happy with music therapy and are continuing to provide it for Pallav.

DISCUSSION

In both cases, the CBR facilitators described the use of music in CBR to support the physiotherapy goals for Ranjit and Pallav. Music motivated the youngsters to participate actively, rather than passively, in their rehabilitation. It also

motivated their family members and friends to get involved in CBR and continue rehabilitation when the facilitators were absent. Specifically, CBR facilitators noticed that:

- Music-based activities motivated Ranjit and Pallav to participate actively in CBR and provided a distraction from discomfort.
- Music-based activities allowed Pallav to explore concepts like fast/slow, start/stop, loud/quiet, leading/following and taking turns.
- Instrument- playing supported fine and gross motor development for Ranjit and Pallav.
- Music-based activities provided opportunities for social inclusion. Family and community members became interested and more involved in CBR.
- Music-based activities provided structure and motivation for families to continue CBR activities throughout the week.
- Music-based activities provided enjoyment and fun for Pallav and Ranjit, their families and their wider community.

CBR facilitators and the involved families used a variety of music activities with these two young people. They drew on the music therapy-based techniques shared in workshops, and also on their own existing music skills, equipment, and interests.

CONCLUSION

The authors of this report believe that other CBR facilitators may similarly benefit from incorporating shared music-making into their CBR work to address SMART goals and promote active participation and family/community engagement; also, to bring joy and fun into their interactions with one another in CBR.

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

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

* * * * *

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