DISABILITY, CBR & INCLUSIVE DEVELOPMENT

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Editorial

Balancing between Rehabilitation and Inclusion and not ignoring the most valuable resource in Society

Community Based Rehabilitation (CBR) was formally initiated by the World Health Organisation (WHO) in the year 1978. Most people will remember this year as the one in which 122 National States committed themselves to foster Primary Health Care (PHC); addressing the main health problems in the community, as well as providing promotive, preventive, curative and rehabilitative services. As much as PHC - in fact - did already exist long before its formal launch by the World Health Organisation, so did CBR before its formal launch. In fact, it existed for centuries in the daily practice of people who had no access to rehabilitative services but who had to cope with their own disability or the disability of relatives and who had to find solutions to the challenges they experienced in daily life. It of course is true that CBR did evolve over the past few decades, from paying attention to improve and increase access to formal rehabilitation services into a more community-development approach. In such a model, increasingly attention is given to a much-needed transformation of society in which people with and without disabilities have equal rights and opportunities. As such, CBR became a model that is no longer directed solemnly on individuals with disabilities but now also has the community as its target in order to make sure that those with disabilities can claim their rights and entitlements. The unique focus on the individual needs of people with disabilities, as well as need to transform society is at the core of what CBR is all about. It seems, however, that this is still not well-understood by those who criticise this approach or maybe even more, this philosophy…

Nowadays this unique twin-track approach seems to be ripped apart in 2 relative new approaches: i.e.

1) the WHO increasingly focusses on access to rehabilitation within Universal Health Coverage (UHC) and it is hoped that with the Rehab2030 Action Plan, rehabilitation will indeed become accessible and available to everyone even to the so often unreached; the poorest of the poor living in the most remote and peripheral parts of societies; and

2) Community Based Inclusive Development (CBID), which in fact is not the equivalent of CBR but rather a fundamentally different approach that is

> directed at systems development or in other words, an approach directed at the realisation of a just, more egalitarian society with equal opportunities for all.

Time will tell us what the impact of this division is and the disability world as well as the rehabilitation sector should take stock of this development within the coming years. It is sincerely hoped that both developments will lead to the so much needed changes so many people are longing for.

In the midst of all these developments we notice, however, that within both aforementioned approaches, those promoting them seem to have little attention for the most vulnerable groups in society: children with disabilities. They also hardly recognise the immense importance and value of caregivers within the family: usually women and mostly mothers, sisters or grandmothers of relatives with disabilities. Both groups are hardly represented within the (global) disability movement. Their voice is seldomly being heard and yet their needs are often the biggest. On the other hand, one sees in low- and middle-income countries that it is the group of children with serious neurodevelopmental disabilities who lack access to good quality rehabilitation services. In the basic training of rehabilitation personnel - all over the world - hardly any attention is given to childhood disability and rehabilitation. Curricula of training of therapists in many low- and middle-income countries are copied from those in high-income countries, and the relevance of the work done by graduates is in general marginal for children with neurodevelopmental disabilities.

A greater focus on the untapped and fundamental resources of informal - family - caregivers is sensible and so much needed. It is the women in most societies who care for their disabled relatives; it the mothers who endlessly try to help their disabled children to eat, to move, to develop. They are the ones offering 24-hour care; they support and encourage their relatives with disabilities to participate in family life and society.

Lessons from projects which, for instance, do consider the importance of informal - family - caregivers in providing rehabilitation to their children with neurodevelopmental disabilities show that one cannot do without them. The rehabilitation physician; the therapist; and even the rehabilitation field worker is never able to seriously contribute to the improvement of the child without a close involvement of mothers or other women in the family. As such their work consists largely about coaching, training and supporting families. It was the late disability scholar Mike Miles who stated decades ago already that CBR was mostly about mothers and he pleaded on several occasions for CBR to be re-named into MBR: Mother Based Rehabilitation. And although that probably is a too small basis as it is often siblings and grandmothers that play a significant role in the parenting process as well, it is crucial and urgent for all those who work in the field of disability and development to recognise both in advocacy and lobby, but also in policy and planning, the enormous value of family members supporting a relative with a disability.

Huib Cornielje
Editor-in-Chief

ORIGINAL RESEARCH

Disability, Sociodemographics, and Discrimination: A Descriptive Analysis of Household Survey Data from Bangladesh

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ABSTRACT

Purpose*: Disability affects upwards of one billion people worldwide, the majority of whom live in low- and middle-income countries. Based on survey data from Bangladesh, the aim of the study is to contribute to an improved understanding of the experiences of people with disabilities in terms of discrimination, health, and sociodemographic indicators.*

Method*: A descriptive analysis of data is presented, from a survey implemented in 2016 on a sample of adult persons with disabilities from 18 districts in Bangladesh (n=1,900). The summary statistics of main indicators and correlation analysis of key variables are given.*

Results*: Women comprised around 40% of the sample. The mean age was 36 years (minimum 18 years and maximum 55 years). Women had lower socioeconomic status than men (p<0, 01), were less likely to be well-educated or employed, had worse self-assessed health (p<0, 05), and were less likely to be able to read and write. Men were more likely to have a physical disability than women (p<0, 01). Both women and men reported unmet needs in terms of access to assistive products and not receiving a benefit. Around 40 % of the sample reported having experienced discrimination, with no significant differences between women and men.*

Conclusion and Implications*: Many women and men with disability experience some forms of discrimination, including in matters pertaining to*

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healthcare, education, and employment. Such experiences may have a negative impact on their life chances. However, women and men with a disability differ in several important respects, both in terms of socioeconomic status and types of disability. Such differences need to be considered for effective and equitable policy development.

***Key words**: disability, discrimination, self-assessed health, Bangladesh, survey*

INTRODUCTION

Various forms of disability continue to affect hundreds of millions of people across most countries and regions of the world. Global estimates suggest that upwards of one billion people are living with a disability (WHO and World Bank, 2011). The vast majority of people with disabilities live in low-income countries (LICs) where the risk of disability is high and the resources available to improve their lives are scarce (Mont, 2007).

While it is important to understand the prevalence of disability across and within countries in order to address the overall needs for investing in preventive, rehabilitative and accessible services, it is also critical to have a broader and deeper understanding of the lives of people living with a disability. In particular, a more profound appreciation of the experiences of people with disability in their everyday lives, in terms of working, seeking healthcare and obtaining education, would contribute towards the development of more effective policy interventions (Borg et al, 2011; Barber, 2012; Barrett and Marshall, 2013; Bowes et al, 2013).

Compared with other members of society, the living conditions of people with disabilities are generally more challenging. Studies have shown that they usually have more difficulties in accessing services, securing an income, and fulfilling their potentials (Potts, 2005; van Brakel et al, 2012). In addition, many people with disabilities, not least in low- and middle-income countries, experience various forms of discrimination that negatively affect their life chances (Cleary, 1997; Carter and Markham, 2001; Erridge, 2005; Turner et al, 2005; Barber, 2012). For example, due to misplaced notions and preconceptions on the part of the general population, persons with disabilities may have less access to healthcare, reduced chances of obtaining or completing an education, or of being accepted for employment (Bjelland et al, 2010; Noone, 2013).

While the current evidence base on the prevalence and experiences of people with disabilities is growing, important gaps remain. For instance, there is still limited knowledge about the experiences of discrimination among persons with disabilities (FHI, 2006; Ali et al, 2013) and their access to social capital (Dutt and Webber, 2010; Gotto et al, 2010). The purpose of this study is to contribute to a broader understanding of the experiences of people with disabilities. In particular, the study presents a descriptive analysis of the findings of the Social Capital and Discrimination in Bangladesh (SCDB) survey of people with disabilities, implemented in 2016. The SCDB survey collected information on a range of issues, including experiences of discrimination, sociodemographic and economic factors, access to social capital, ability to perform various tasks, and on use of assistive products.

Study Context

In Bangladesh, a country of around 160 million people, estimates of the prevalence of disability vary considerably across different studies, from less than 1% in Census surveys to over 14% in a household survey (Titumir and Hossain, 2005; Bangladesh Bureau of Statistics, 2015). The most common types of disabling impairments in Bangladesh are visual (32.2% of the total estimate), physical (27.8%), hearing (18.6%), intellectual (6.7%), multiple (10.7%), and speech (3.9%) (BBS, 2015). Existing surveys also show that the prevalence of different types of disability varies among demographic groups and with socioeconomic status.

While Bangladesh has signed the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and extensive support is provided by the civil society to realise the aim of the Convention, the lives of people with disabilities in Bangladesh continue to be affected by negative norms and attitudes(Titumir and Hossain, 2005). For example, around one-third of the general adult population of Bangladesh has poor knowledge of people with disabilities, and many have a weak understanding of the causes of disability. Critically, attitudes of the general population toward people with disabilities include name-calling and refusing to let offspring marry a person with a disability (ibid). Such attitudes are not unique to Bangladesh, making the lessons from this study context valuable to other low- and middle-income countries as well.

METHOD

Study Design

The SCDB survey was a cross-sectional household survey conducted between April and September 2016 in Bangladesh. The survey was implemented in four divisions of Bangladesh, covering a total of 18 Districts, two of which were municipalities (urban).

Study Sample

The sampling frame of the survey consisted of all people with disability who were registered as such under the Promoting Rights of People with Disabilities (PRPD-DI) project. The PRPD-DI project was implemented by the national non-governmental organisation - Centre for Disability in Development (CDD) - in all regions of the country. Under this project, CDD worked with a number of partner NGOs (P-NGO) to implement a series of activities. (Details are available at http://www.cdd.org.bd/key-focus-areas/current-projects.)

In total, 9920 individuals were included in the original list of participants of the PRPD-DI project. A total of 4816 individuals fulfilled the eligibility criteria of the SCDB survey: adults between 18 and 55 years of age, with a hearing, speech, visual, physical, or combination impairment. To ensure that first-hand information was provided, the study excluded children and persons with a mental or cognitive disability. The participants were randomly selected from the sample frame, employing non-stratified sampling. Based on pre-study power calculations, the aim of the study was to sample around 2,000 individuals to ensure sufficient power of the statistical analysis.

Data Collection

The SCDB household survey questionnaire consisted of a total of 97 questions divided into five separate sections: a) Location; b) Identification, Demographics, and Family; c) Disability; d) Socioeconomics; e) Social Capital; and, f) Discrimination. The draft questionnaire was submitted along with an application to the Bangladesh Medical Research Council (BMRC) for ethical approval. No changes were made to the questionnaire after ethical review and subsequent approval.

The implementation of the survey was led and coordinated by a team of researchers at the CDD headquarters outside of Dhaka. All the interviewers (n=12) had previous experience in administering a household survey questionnaire involving face-to-face interviews with the interviewers filling in the responses. The team of interviewers was given training on how to administer the survey during two separate events, each of which involved testing the survey questionnaire on persons with disabilities. Among other quality control activities, the interviewers were instructed to check that all relevant questions had been addressed and that only legitimate values had been entered. After further post-survey data quality controls, the final sample of the SCDB survey consisted of 1900 respondents.

Statistical Analysis

To provide a detailed description of the main results of the SCDB survey, the data was analysed by means of descriptive statistics and bivariate correlation analysis. The categorical variables are described by means of frequencies and proportions across categories. The continuous variables are presented along means, range, and standard deviations. In addition, graphical illustrations of socioeconomic status across sex and disability are presented.

To obtain an understanding of the association between the sociodemographic characteristics of the sample and relevant indicators of disability, discrimination, and other variables, Pearson's Chi-squared tests of association were used along with probability values. Differences in mean values for selected groups were analysed by independent sample t-tests. In addition, measures of association were calculated using Chi-squared and non-parametric tests (Wilcoxon rank-sum) statistic. All statistical analyses were made in Stata 16.1.

Ethical Approval

The study received ethical approval from the Bangladesh Medical Research Council (MCRC), reference number BMRC/NREC/2013-2016/621. Before the interviews started, all participants were informed about the aim of the research study, their right to decline to participate, and how the information provided would be handled by the researcher. They were also provided with the contact details of the principal investigators. Each participant then signed a consent form.

RESULTS

This section presents the results of the descriptive analysis of the survey data. The first sub-section looks at the overall distribution of the main demographic and socioeconomic variables by sex. The second sub-section presents the analysed results of the correlation between various indicators of relevance to people living with a disability, such as access to assistive devices, a mobile phone or the internet, levels of literacy, and the ability to perform certain everyday activities. These indicators are presented by sex and type of disability. The next sub-section looks at experiences of discrimination, and the final sub-section presents the results of the statistical analyses of the relationship between key indicators, including sex, income, and self-assessed health (SAH).

Demographics and Socioeconomic Status by Sex

As noted above, the SCDB survey applied a non-stratified sampling approach to identify the individuals to be included in the survey. This resulted in around 42% of the sample being women and around 58% being men (Table 1).

Table 1: Demographics, Socioeconomic Status, and Disability by Sex

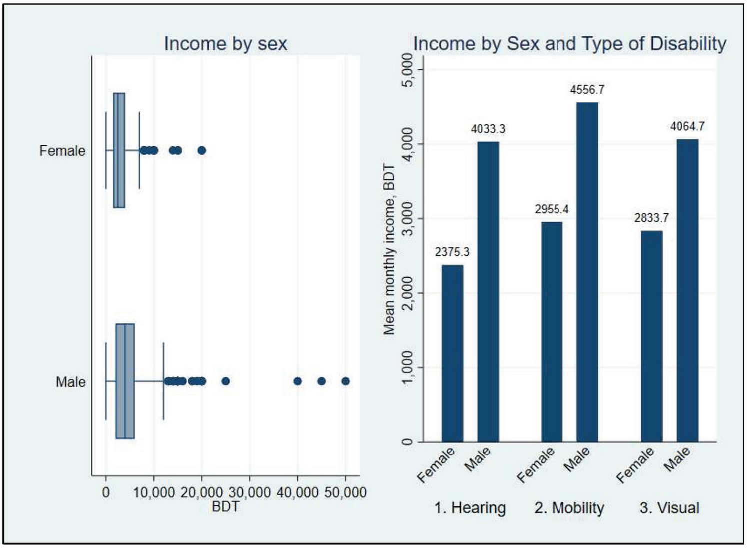
	Female (N = 804)	Male (N = 1096)	Total (N = 1900)
Age			
Mean (SD)	35.4 (10.3)	36.0 (10.3)	35.7 (10.3)
Median (Q1, Q3)	34.0 (27.0, 44.0)	35.0 (28.0, 44.0)	34.0 (27.5, 44.0)
Min, Max	18, 55	18, 55	18, 55
Monthly spending (BDT)			
Mean (SD)	2816 (2087)	4394 (3711)	3726 (3223)
Median (Q1, Q3)	2500 (1500, 4000)	4000 (2000, 6000)	3000 (2000, 5000)
Min, Max	0, 20000	0, 50000	0, 50000
Sex			
Female	804 (100%)		804 (42.3%)
Male		1096 (100%)	1096 (57.7%)
Disability type			
Hearing	162 (20.2%)	150 (13.7%)	312 (16.5%)
Mobility	466 (58.0%)	742 (67.9%)	1208 (63.7%)
Visual	175 (21.8%)	201 (18.4%)	376 (19.8%)
Duration of problem			
Less than 1 year	3 (0.4%)	5 (0.5%)	8 (0.4%)
Between 1 and 5 years	38 (4.8%)	53 (5.0%)	91 (4.9%)
More than 5 years	351 (44.4%)	543 (50.8%)	894 (48.1%)
Always	399 (50.4%)	467 (43.7%)	866 (46.6%)
Location			
Urban	159 (19.8%)	165 (15.1%)	324 (17.1%)
Rural	645 (80.2%)	931 (84.9%)	1576 (82.9%)
Education			
No education	513 (64.8%)	587 (54.4%)	1100 (58.8%)
Primary	157 (19.8%)	222 (20.6%)	379 (20.3%)
Secondary	95 (12.0%)	198 (18.4%)	293 (15.7%)
Higher secondary	11 (1.4%)	41 (3.8%)	52 (2.8%)
Post-secondary	16 (2.0%)	31 (2.9%)	47 (2.5%)
Employment status			
Unemployed	686 (85.9%)	462 (42.4%)	1148 (60.8%)
Employed	113 (14.1%)	627 (57.6%)	740 (39.2%)

The mean age of the participants was around 36 years. The median age was 34 years, indicating a fairly normal age distribution of this sample of adults aged between 18 and 55 years. There was no difference in the distribution of age between women and men. Most people with a disability in the sample were affected by mobility impairment. Around 47% of the sample reported being born with the disability, and almost half of the participants had been affected by the disability for more than five years before the implementation of the survey. While there were fairly equal numbers of men and women who were affected by a visual or hearing impairment, men were significantly more likely to be affected by a mobility impairment, although the association is not very strong (p<0.01; Cramér's V=0.1064; not shown).

The vast majority of participants reported having no formal education. This was similar for both women and men, although a slightly larger share of the men had reached the highest education level (post-secondary). Around 61% of the total sample reported currently being unemployed, and women were more likely to be unemployed than men.

Income was measured by personal monthly spending in Bangladesh *thaka* (BDT). The mean income of the sample was 3726 BDT (around USD 43). However, on average, the women earned less than two-thirds of the men. The considerably lower average and more concentrated income distribution among women is illustrated in Figure 1 (left-hand panel).

Figure 1: Income by Sex (SCDB survey, 2016)



The differences in mean income go across all three types of disability (Figure 1, right-hand panel). Both women and men with mobility impairment tended to earn more than those with a visual or hearing impairment. Likewise, both women and men with a hearing impairment tended to earn less.

Health, Social Capital, Assistive Products, and Abilities

Table 2 shows the frequency and shares across sex of some of the main analytical indicators on which the survey collected data. Around 45% of the respondents reported their overall health to be "*good*". However, more than half of the sample assessed their health to be less than good, with more than 8% saying their health was "*very bad*".

Table 2: Self-assessed Health, Access to Technology, and Abilities by Sex

	Female (N = 804)	**Male (N = 1096)**	**Total (N = 1900)**
SAH			
Very bad	76 (9.5%)	80 (7.3%)	156 (8.2%)
Bad	160 (19.9%)	193 (17.7%)	353 (18.6%)
Neither bad nor good	206 (25.7%)	295 (27.0%)	501 (26.4%)
Good	354 (44.1%)	509 (46.6%)	863 (45.5%)
Very good	7 (0.9%)	16 (1.5%)	23 (1.2%)
People can be trusted			
No	336 (43.5%)	382 (36.0%)	718 (39.1%)
Yes	436 (56.5%)	680 (64.0%)	1116 (60.9%)
Member in groups			
No	587 (73.0%)	726 (66.2%)	1313 (69.1%)
Yes	217 (27.0%)	370 (33.8%)	587 (30.9%)
Problem walking			
No problem	340 (42.4%)	409 (37.5%)	749 (39.6%)
Mild problem	71 (8.9%)	104 (9.5%)	175 (9.2%)
Moderate problem	113 (14.1%)	143 (13.1%)	256 (13.5%)
Severe problem	184 (22.9%)	267 (24.5%)	451 (23.8%)
Complete problem	94 (11.7%)	167 (15.3%)	261 (13.8%)
Problem using hands			
No problem	460 (57.8%)	636 (58.5%)	1096 (58.2%)
Mild problem	71 (8.9%)	96 (8.8%)	167 (8.9%)
Moderate problem	86 (10.8%)	107 (9.8%)	193 (10.2%)
Severe problem	117 (14.7%)	157 (14.4%)	274 (14.5%)
Complete problem	62 (7.8%)	92 (8.5%)	154 (8.2%)
Able to write			
No	539 (68.0%)	629 (58.3%)	1168 (62.4%)
Yes	254 (32.0%)	450 (41.7%)	704 (37.6%)
Able to read			
Yes	144 (17.9%)	280 (25.7%)	424 (22.4%)
Yes with some problems	90 (11.2%)	148 (13.6%)	238 (12.6%)
No usually not	91 (11.3%)	111 (10.2%)	202 (10.7%)
No not at all	478 (59.5%)	551 (50.6%)	1029 (54.4%)
Disability benefit			
No	560 (69.7%)	722 (65.9%)	1282 (67.5%)
Yes	244 (30.3%)	374 (34.1%)	618 (32.5%)
Use of assistive products			
No	679 (84.7%)	789 (72.1%)	1468 (77.4%)
Yes	123 (15.3%)	305 (27.9%)	428 (22.6%)
Access to cell phone			
No	299 (37.5%)	278 (25.6%)	577 (30.6%)
Yes	498 (62.5%)	810 (74.4%)	1308 (69.4%)
Access to internet			
No	765 (96.1%)	1016 (93.0%)	1781 (94.3%)
Yes	31 (3.9%)	76 (7.0%)	107 (5.7%)

With respect to social capital, two different types of indicators were included. First, slightly less than two-thirds of the entire sample agreed with the statement that people can generally be trusted (an indicator of cognitive social capital) (Kawachi et al, 2008). However, a larger share of men did so, compared to women. Second, around one-third of the total sample reported being a member of at least two social groups, such as an association, a cooperative, or a religious congregation (an indicator of structural social capital) (ibid). A slightly larger share of men than women reported being a member of at least two such organisations.

More than 60% of the respondents said they experienced some problems with walking. While such a problem may be predominantly concentrated among those with a mobility impairment, further analysis showed that those with a hearing (and vision) impairment also reported having some problems moving about (not shown).

The vast majority of respondents reported not being able to write, did not use an assistive product, and did not receive any form of disability benefit. Furthermore, a larger share of women than men reported not being able to read. Finally, while more than two-thirds reported that they had access to a mobile phone (of any type), the majority of respondents did not have access to the internet. The shares for women and men were similar for these indicators.

Disability and Discrimination

The SCDB survey asked several questions about the respondents' experiences of discrimination. Discrimination was defined in the survey as "being treated negatively in some sense or situation." (See SCDB Questionnaire, Section F: Discrimination, for details). Overall, around 40% of the participants reported having been discriminated against at some point in life in some unspecified context (Table 3, Panel A).

Table 3: Ever been Discriminated Against (Panel A) and Discriminated in past 12 months (Panel B)

Panel A

Ever been discriminated	Freq.	Percent
No	1,123	60
Yes	743	40
Total	1,866	100

Panel B

Discriminated in past 12 months	Freq.	Percent
No	177	23
Yes	605	77
Total	782	100

Among those who reported having experienced discrimination, around 77 % confirmed that this had happened in the past 12 months (Panel B).

While these are noteworthy shares, there was no evidence that women living with a disability were more at risk of discrimination than men (Table 4, Panel A) or that persons afflicted by a particular type of disability were more prone to discrimination than others (Panel B).

Table 4: Discrimination by Sex (Panel A) and Disability Type (Panel B)

Panel A

Ever been discriminated	**No**	**Yes**	**Total**
Female	485	310	795
	478	317	795
	61	39	100
	43	42	43
Male	638	433	1,071
	645	426	1,071
	60	40	100
	57	58	57
Total	1,123	743	1,866
	1,123	743	1,866
	60	40	100
	100	100	100

Pearson chi2(1) = 0.3925 Pr = 0.531

Cramér's V = 0.0145

Panel B

Ever been discriminated	**Hearing**	**Mobility**	**Visual**	**Total**
No	171	733	219	1,123
	185	715	223	1,123
	15	65	20	100
	56	62	59	60
Yes	136	453	150	739
	122	471	147	739
	18	61	20	100
	44	38	41	40
Total	307	1,186	369	1,862
	307	1,186	369	1,862
	16	64	20	100
	100	100	100	100

Pearson chi2(2) = 3.9740 Pr = 0.137

Cramér's V = 0.0462

(Note: Total frequency; Expected frequency; Row percentage; Column percentage)

Statistical and Sensitivity Analyses

In addition to the above analyses of the survey sample, statistical analyses were performed to measure the relationship between selected variables. Table 5 shows the result of a two-sample test of the differences in mean income by sex.

Table 5: Two-sample Test of Differences in Mean Income by Sex

Group	N	Mean	Std. Err.	Std. Dev.	[95% CI]	
Female	804	2,815.80	73.60	2,086.78	2,671.34	2,960.26
Male	1,096	4,394.21	112.09	3,710.90	4,174.27	4,614.15
Combined	1,900	3,726.29	73.95	3,223.40	3,581.26	3,871.32
Differences		-1,578.41	134.09		-1,841.41	-1,315.42

H0: diff=0, H1: diff<0, Pr(T<t)=0.0000. t=-11.7711, Satterthwaite d.f.=1789.16.

The differences reported above were statistically significant (p<0.01). Furthermore, the estimated mean difference of income of around 1600 BDT was close to half of the estimated standard deviation, indicating that the effect is relatively strong.

With respect to the reported difference in self-assessed health between men and women in the current sample, there was some support for this measure of overall health being significantly better among men compared with women (p<0.05) (Table 6).

Table 6: Two-sample Wilcoxon rank-sum (Mann-Whitney) test of difference in Self-Assessed Health (SAH) by Sex

Group	N	Rank sum	Expected
Female	803	73,9469.0	7,61,645.5
Male	1,093	10,58,887.0	10,36,710.5
Combined	1,896	17,98,356.0	17,98,356.0

H0: SAH female = SAH male; z=-2.007, Prob>|z|=0.0448

Similar two-sample tests of proportions for the indicators reported above were conducted. The results suggest that the reported differences between men and women are statistically significant at p<0.01 for employment status, literacy, use of assistive product, access to benefits, and access to mobile phone (not shown).

In addition, as noted above, the share of women in the current sample appeared to be larger than that reported in other recent studies of disability in Bangladesh (BBS, 2015). To adjust for this over-sampling, the above set of analyses was repeated using population weights for sex. However, the results of the weighted estimates did not produce any material differences to those reported above.

Finally, a power analysis was performed to assess the overall validity of the survey sample in terms of size. The test used Stata's chi2power-command set at sample size factor 1 with increments of 1 to factor 10. The test showed that for power size factor of 1 (i.e., the actual sample size of n≈1896 individuals), the power was 0.9899, suggesting that the sample size was adequate for the types of analyses conducted above (not shown).

DISCUSSION

Using data from a household survey about the lives of people living with disability in various districts throughout Bangladesh, the study found several aspects that are worth noting. There are considerable and important variations to be found among the group of people living with disabilities. Women and men are affected by different types of disabilities, and their economic and social experiences vary. In line with the general situation of women in Bangladesh and elsewhere, women respondents in the current survey tend to be poorer, less able to read and write, use an assistive product to a lesser extent, have less access to a mobile phone, and are in worse health than the men.

While the study does not aim to make statistical inferences with respect to the relationships between the various indicators presented in the analysis, the noteworthy finding is that around 40% of the sample reported having experienced discrimination of some sort. Underscoring the risk of discrimination and social stigma, a previous study in Bangladesh with a sample of 583 participants with hearing or mobility limitations, between 15-55 years of age, found that about six out of ten respondents had experienced negative attitudes from neighbours. They also reported difficulties in making and maintaining friendships (Borg et al, 2012). The implications and effects of such behaviours and attitudes on the part of the general population towards people with disabilities most likely varies across contexts. However, a general understanding of the nature and scope of these issues is important for effective interventions aiming to improve the lives of people living with a disability.

The findings of this study complement those of other investigations into the prevalence, impacts, and experiences of people living with disability in Bangladesh. The current study extends the understanding of these issues by focusing on a set of key indicators and factors of relevance, including types of disabilities, differences between women and men, and experiences of discrimination. While all contexts are particular, several of these findings can be translated to other countries and regions. For example, the risk of discrimination is likely to be real in most, if not all, contexts where people with disabilities live (Erridge, 2005; Hanna and Linden, 2009; Échevin, 2013). Likewise, the seemingly poorer outcomes for women with disabilities as compared with men are also all but universal.

The study also found that people with disabilities in Bangladesh have access to different types of social capital, both cognitive and structural. The evidence for the role of social capital in improving population health and for reducing the risk or prevalence of discrimination is relatively strong (Erridge, 2005; Derose and Varda, 2009; Gotto et al, 2010; Eriksson, 2011). Developing and implementing interventions to support access to social capital for people with disabilities would thus appear to be a matter of priority. However, the results also show that women and men differ with respect to social capital. This means that care needs to be taken when designing such interventions in order to ensure their effectiveness and fairness.

Although care should be taken with respect to concrete policy implications, the findings from a descriptive analysis such as this one do suggest that policies to address the needs of people living with disabilities need to take into careful consideration the diversity in experiences, abilities, and opportunities of these groups of individuals. Indeed, people living with disabilities often have idiosyncratic needs and abilities. The capacity of others to address these needs requires particular and individually tailored solutions. Broadly however, actions should be taken to reduce the risk of discrimination against people living with disability so as to ensure that their human and civil rights are protected.

Further analysis is needed to understand the causal directions of some of the associations included in the study. Such analyses are challenging, given the complex nature of the processes of the impact of discrimination on social and economic outcomes. Furthermore, discrimination takes many different forms and is experienced in different contexts. Additional analysis of the SCDB survey data will contribute to a more profound understanding of some of these questions.

Limitations

There are several limitations of the study that need to be taken into consideration when interpreting the results. First, while the sample is relatively large for this type of study, it is not nationally representative. A large category of disability, namely that of cognitive and mental disability, is not included in the study. Also, the study only looks at adult individuals. The experiences of children and young people living with disability most likely differ in important ways from those of adults. Broad generalisations based on this study alone should therefore be avoided.

In addition, and as noted above, the study adopts descriptive univariate and bivariate analysis of the survey data to investigate distributions of and associations between variables of relevance. In combination with the cross-sectional study design this precludes any causal analysis of relationships.

CONCLUSION

Based on the above results and limitations, the study concludes that people living with disabilities make up a diverse group of individuals whose specific abilities and challenges need to be considered for effective policy development. The situation of women with disabilities differs significantly in some respects from that of men, and these differences also need to be properly understood when designing interventions to support people with disabilities. Finally, both women and men living with disabilities experience discrimination in different situations. Such experiences most likely affect people with disabilities in a negative way, and policies should be developed to reduce the risk of such experiences and limit their impacts.

Implications for Rehabilitation

- People living with a disability frequently experience various forms of discrimination with respect to healthcare, education, and employment.
- Interventions to support people with disabilities need to consider the heterogeneity of individuals, both across sex and socioeconomic status as well as by type of disability.
- Differences between women and men are of particular concern for effective and equitable policy development.
- Further research is needed to understand the role of social capital to mitigate the risk of being discriminated against in various contexts.

ACKNOWLEDGEMENT

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All contributing authors participated in the planning of the study, including its design, sampling approach, and questionnaire development. The corresponding author can be contacted for any queries related to the data used in the study.

Conflict of Interest

The authors declare no conflict of interest. The current study did not aim to evaluate the effects of the work of CDD or its partner NGOs in any way.

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Effectiveness of Community-Based Rehabilitation on the lives of Parents of Children with Cerebral Palsy: A Mixed Method Study in Karnataka, India

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ABSTRACT

Purpose: *The study aimed to identify the effects of the CBR programme on parents of children with Cerebral Palsy, living in Karnataka State, India. It also tried to find the challenges and improvements needed to make the CBR programme more effective.*

Method: *A cross-sectional, descriptive study design was used to collect a sample of 100 parents of children with Cerebral Palsy, with GMFCS levels IV and V. The sample was drawn from various communities in Bangalore, Davanagere and Bijapur, where the services of The Association of People with Disability are available. Face-to-face interviews were conducted with the study subjects. Data was analysed by SPSS using descriptive and inferential statistics.*

Results: *It was observed that the CBR programme had a positive effect on parents' health, knowledge, social lives and empowerment. A binary logistic regression was done to find the relationship between health, knowledge, social lives and assistive devices use. A strong association was found between all the areas (p=.001) except GMFCS and assistive devices use (p=.004) at 95% CI. The odds ratios between them were greater than 1 and showed the strong positive effect of the CBR programme on parents.*

Conclusion: *The CBR programme not only has a positive effect on children with Cerebral Palsy, but also plays an important role in parents' lives. It contributes in a positive way to parents' overall activity.*

Key words: *Cerebral Palsy, CBR, Rehabilitation, GMFCS, Parents*

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INTRODUCTION

People with disability belong to one of the poorest and most marginalised groups in the society, accounting for approximately 15% of the world's population (World Health Organisation, 2011). To decrease the burden for persons with disabilities in low-income countries, the World Health Organisation (WHO) initiated Community-Based Rehabilitation (CBR) four decades ago (Khasnabis et al, 2010). CBR programmes have been recognised as exceptionally successful methods for advancing the rights and opportunities of people with disabilities (Mauro et al, 2014). Despite the fact that people with disabilities in low- and middle-income countries access rehabilitation services primarily via CBR programmes, there is hardly any literature that provides rigorous evaluation (Fuzikawa, 2008; Mauro et al, 2014).

Cerebral Palsy is a common childhood disability and is associated with life-long disability. Children with Cerebral Palsy experience sensory, motor, speech and cognitive impairment (Brannan & Heflinger, 2006; Pakula et al, 2009). The estimated incidence of Cerebral Palsy worldwide is 2 to 2.5 per 1000 live births (Sankar & Mundkur, 2005) and around 3/1000 live births in India (Vyas et al, 2013). Being a developing country, the actual figure might be considerably higher (Vyas et al, 2013). Impairments may lead to various functional limitations which, in turn, may require assistance in activities of daily living throughout the life of an individual with Cerebral Palsy. Some studies show that taking care of a child is part of normal parenthood; however, the excessive demands associated with taking care of a child with a disability may lead to increased burden/ strain.

Negative health outcomes among caregivers associated with their children with a long-term health condition have been reported; for instance, depression, stress, anxiety and low self-efficacy (Murphy et al, 2007; Lee et al, 2009; Cadman et al, 2012). Mothers of children with intellectual disabilities reported lower levels of happiness, self-esteem and self-efficacy than mothers of children without intellectual disabilities (Emerson et al, 2007). In general, the challenges faced by caregivers include psychological issues owing to the demands of caregiving. Furthermore, uncertainties and physical health challenges in parents of children with disabilities emanate from excessive stress and may be related to constantly assisting their children in activities of daily living, and thus add to the mental strain of parents (Tonga & Düger, 2008; Sajedi et al, 2010; Dambi & Jelsma, 2014). Mothers often experience socio-economic challenges (Olaogun et al, 2006; Singogo et al, 2015) as well as marital problems (Vijesh & Sukumaran, 2007; Singogo, et al, 2015). Apart from social isolation and marital problems, research has found that mothers experienced negative attitudes from family, friends, community members and healthcare professionals (Jette, 2006; Resch et al, 2010; Woodgate et al, 2015). Hence, the challenges faced by caregivers, mainly mothers of children with Cerebral Palsy, could be viewed within a bio-psychosocial model of disability (WHO, 2001; Singogo et al, 2015). It is therefore evident that the quality of life (QoL) of these mothers is negatively affected as a result of caring for their children with Cerebral Palsy (Green, 2003). Thinking about a child with Cerebral Palsy may be overpowering, resulting in distress and anguish as the truth of lost expectations and dreams become evident (Huang et al, 2010).

The level of required assistance depends on the severity of impairments, activity limitations and participation restrictions (Jette, 2006). Physical barriers also serve as major problems. The physical environment creates challenges because of lack of sidewalks, ramps, functioning lifts and small indoor spaces (Edwards & Tsouros, 2006; Evcil, 2009; Singogo et al, 2015).

Implementing CBR programmes in rural and distant zones can be successful in improving the quality of life of people with physical disabilities (Fuzikawa, 2008; Grandisson et al, 2014; Khan et al, 2017). The CBR approach was found effective in overcoming economic, cultural and geographical barriers and was more effective in retaining clients and their families in programmes (Chatterjee et al, 2003). Exploration and assessment of the conditions under which CBR programmes are best for various populations is unquestionably required, with regard to both CBR standards and guidelines for powerful examination and assessment (Grandisson et al, 2014). Carrying out evaluations of CBR programmes is also essential in order to monitor their effectiveness and relevance. Kuipers et al (2008) articulated that without evaluation the effectiveness of CBR is not confirmed, which in turn could affect the integrity of a CBR programme. Since the origination of CBR, there have been an extensive number of CBR evaluations around the world (Chappell & Johannesmeier, 2009).

In a study it was found that apparently CBR has an effect on groups of persons with disability both legitimately and by implication. For instance, direct interventions such as counselling and training of parents of children with disabilities and other family members had an effect on their self-esteem and confidence in dealing with their family member with disability. The study showed that the effectiveness of CBR was not just the result of individual medical rehabilitation interventions, but included aspects of community development, poverty reduction, social inclusion and equalisation of opportunities, as set out in the joint position paper (WHO, 2005) definition of CBR (Engle et al, 2011). Biggeri et al (2012) stated that “the CBR programme evaluated has a positive effect on access to services and the well-being of persons/children with disability who are particularly deprived on outcomes of interest.”

In a study in India, it was found that the quality of life of most of the parents of children with disability was neither good nor bad. Parents interviewed stated that it could be because they had learned to cope with the situation. The major aspect that had been influenced with the CBR programme were socially related, followed by mental aspects. Most of the guardians were happy with their own well-being. The majority of their concerns were because of lower economic status, lack of attention for the illness/disability of their child and the inaccessible healthcare facilities (Chalipat et al, 2016).

A few studies report that Health Related Quality of Life (HRQOL) of mothers of children with Cerebral Palsy is influenced contrarily (White-Koning et al, 2007; Arnaud et al, 2008). While the HRQOL of mothers is reported to be negatively associated with depression, anxiety, educational status, and functional levels, others assert that there is no correlation between the HRQOL of mothers and functional levels of children with Cerebral Palsy (Ones et al, 2005). A study by Diwan et al (2011) found that 70% of mothers having a child with Cerebral Palsy had a mild to severe depression, and that depression was negatively affecting their HRQOL.

Objective

The focus of the study was to identify the effects of the CBR programme on the lives of parents of children with Cerebral Palsy in five areas namely health, knowledge of parents, social lives, home modification and empowerment of parents. It also tried to find the challenges and improvements needed to make the CBR programme more effective in the future.

METHOD

Study Design

This was a cross-sectional study. Mixed methods (qualitative and quantitative) were employed to achieve the objective.

Study Setting

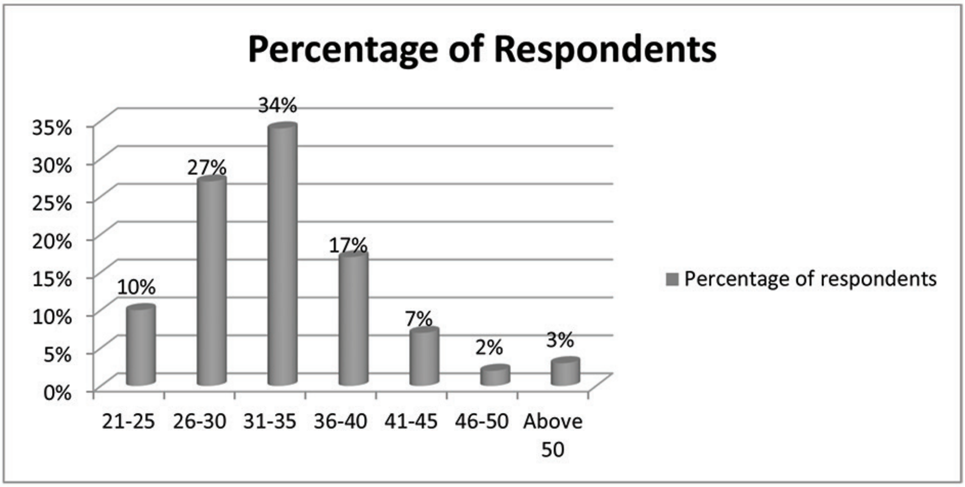
The study was conducted in 3 districts of Karnataka State in India namely Davangere, Bijapur and Bangalore, where The Association of People with Disability (APD) have their network.

Sample

Parents of children with Cerebral Palsy were the target population. Convenience sampling procedure was used to select the potential participants. This non-probability sampling method included all the parents involved in the CBR programme for more than two years. The sample size consisted of 100 participants.

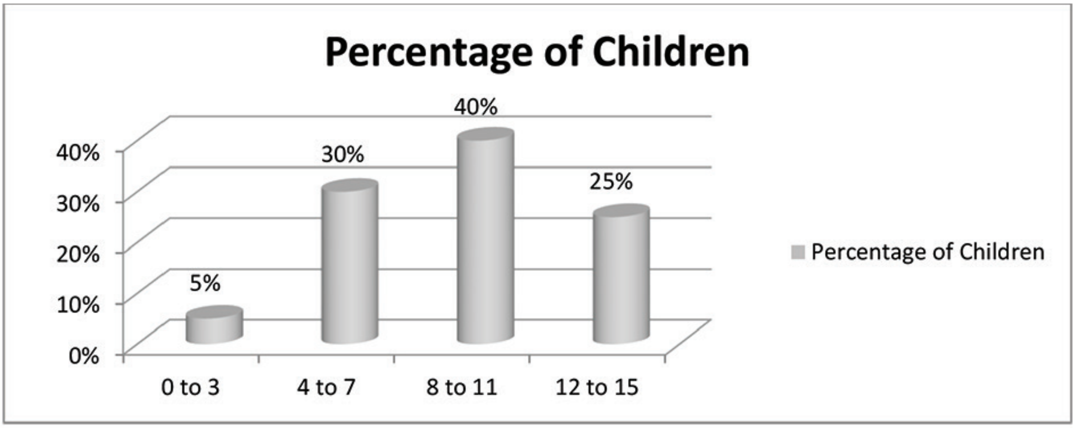
Most of the respondents (34%) were between 31-35 years of age and the smallest group (2%) were in the age group of 46-50 years. The mean age was 33.56 years with a standard deviation of 6.40, ranging from 23-54 years (Figure 1). Among them 92 % were biological mothers and 8 % were biological fathers.

Figure 1: Percentage of Respondents (parents) according to Age Groups



Among the 100 children, most (40%) were between 8-11 years of age and the fewest (5%) were in the age group of 0-3 years. The mean age was 8.99 years with a standard deviation of 3.27, ranging from 6 months to 15 years (Figure 2). Of these children, 29 % were of GMFCS level IV whereas 71% were of GMFCS level V.

Figure 2: Distribution of Children according to Age Group



Data Collection

In-depth information about the existing CBR programme was gathered. Data was collected through interviews as well as a questionnaire completed by individual mothers and fathers who were involved in their children's daily activities. Participants were asked to provide information about their health, social wellbeing, and knowledge about their child's disability and how to handle them with appropriate care and empowerment status i.e. the knowledge about their child's disability. They also were asked to make suggestions for the improvement of the CBR programme.

Study Instrument

The survey questionnaire consisted of 44 questions inquiring about respondents' socio-demographic background, child's disability characteristics, their health, knowledge, social life and empowerment status. It also sought information about the use of assistive device and possible home modifications.

The questionnaire developed for the study was based on a literature review (Grandisson et al, 2014), and had some questions adapted using the following references: WHOQoL-BREF (WHO, 1996), Community Integration Questionnaire (Willer et al, 1993), Burden Scale for Family Caregivers (Graessel et al, 2014), the Zarit Burden Interview (Bédard et al, 2001), Pelvic Floor Impact Questionnaire (PFIQ) -7 (Shirley Ryan Abilitylab, no date). The questionnaire was translated into Kannada, the local language, by a hired professional translator following the standard procedure of linguistic validation. Before data collection was started, a pilot study was conducted with 5 parents of children with Cerebral Palsy who were attending the CBR programme of the Association of People with Disability (APD). This was done to ensure the face validity of the questionnaire. After reviewing the results of pilot study, changes were made, and the final questionnaire was ready to be employed among the 100 participants of this study.

1. Demographic characteristics: Information pertaining to the participants and their children was collected. Maternal characteristics were defined such as the mother's age, educational attainment, marital status, employment status, occupation, number of family members living in the same household, and socio-economic status. The child's characteristics included age and GMFCS levels.

2. Effects on parent's health, knowledge, social life and empowerment was gathered with an adapted scale, which measures the effectiveness of the CBR programme on the parents in various dimensions. There are 16 items on a five-point Likert-type Scale consisting of four areas: health, knowledge, social life, and empowerment. Items are scored from '1'(low) to '5'(high), with higher scores indicative of greater positive effects of the CBR programme on parents. The Scale demonstrated acceptable reliability (Chronbach's $\alpha = 0.83$) for this sample.

3. Assistive Devices and Modifications: The scale was adopted by the authors using similar scales like QUEST (Version 2.0) (Demer et al, 2000) & ATSurvey-1107, (Massachusetts Rehabilitation Commission, 2006) measured the modifications done in various dimensions. This 10-item five-point Likert-type Scale consists of three areas: home modification, established exercise area and assistive devices. Items are scored from '0' (low) to '4' (high), with higher scores indicative of greater changes in the home environment. The Scale demonstrated acceptable reliability (Chronbach's $\alpha = 0.77$) for this sample.

Data Analysis

The data collected was reviewed, recorded and entered into the SPSS programme, in order to reduce human error during analysis.

Ethical Consideration

Ethical approval for conducting research was given by the Institutional Review Board (IRB) of Bangladesh Health Professions Institute (BHPI). Prior permission was taken from the Association of People with Disability (APD) to collect data from areas where it functioned. Informed consent forms as well as questionnaires, in both English and Kannada languages, were submitted along with the research proposal.

Informed consent was taken from individual respondents before data collection. The respondents were informed that they did not need to answer any question with which they were not comfortable. No coercion was used, and confidentiality and anonymity of the obtained information was maintained as per the "right to privacy".

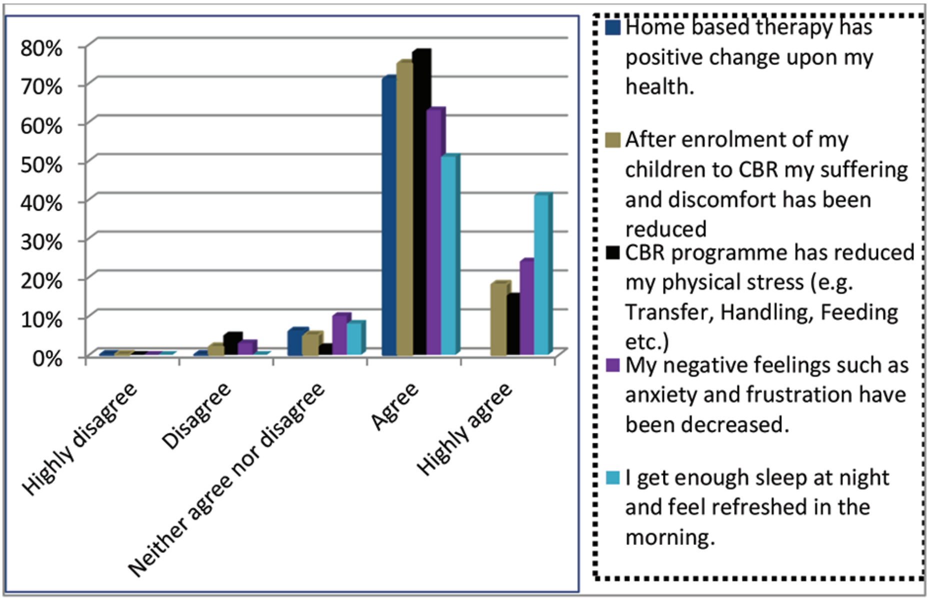
RESULTS

I. Effectiveness of CBR

1. Health

Out of 100 respondents, 71% agreed that home-based therapy had brought about a positive change to their health, 23% highly agreed and 6% neither agreed nor disagreed. While 75% agreed that after enrolment of their child in the CBR programme their suffering and discomfort were reduced, 18% highly agreed, 5% neither agreed nor disagreed, and 2% disagreed. Again, 78% agreed that the CBR programme had reduced their physical stress (e.g. transfer, handling, feeding, etc.), while 15% highly agreed, 5% disagreed and 2% neither agreed nor disagreed. Around 63% of the respondents agreed that their negative feelings such as anxiety and frustration had decreased after enrolling in the CBR programme, followed by 24% who highly agreed, 10% who neither agreed nor disagreed, and 3% who disagreed with this. While 51% of the respondents agreed that they got enough sleep at night and felt refreshed in the morning, 41% highly agreed and 8% neither agreed nor disagreed with this. From the above frequencies it can be said that the CBR programme had a positive effect upon parents' health (Figure 3).

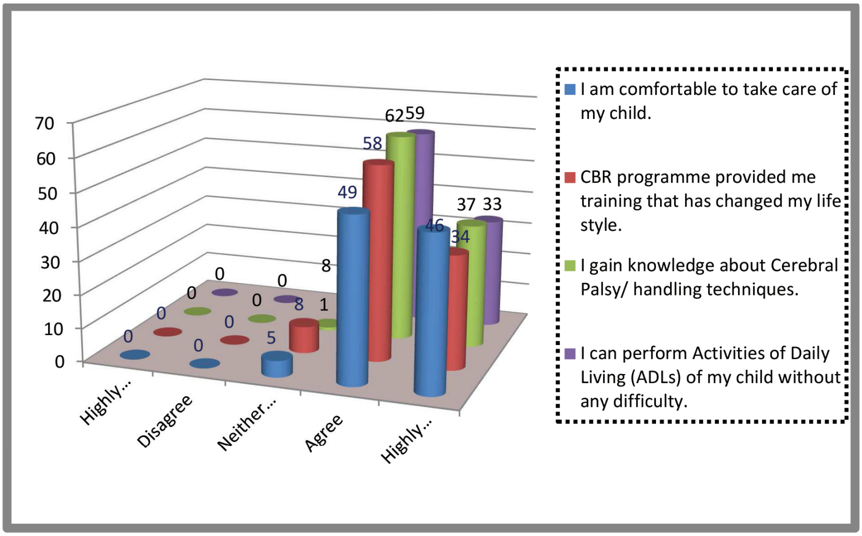
Figure 3: Health Status of the Parents



2. Knowledge of Parents

While 49% agreed that they were comfortable with taking care of their children after the training, 46% highly agreed and 5% neither agreed nor disagreed. There were 58% who agreed that the training provided by the CBR programme had changed their lifestyle, 34% highly agreed, and 8% neither agreed nor disagreed in response to this question. While 62% agreed that they gained knowledge about Cerebral Palsy and how to handle their child in a therapeutic way, 37% highly agreed and 1% neither agreed nor disagreed with this. Most of the respondents or 59% agreed that they could perform Activities of Daily Living of their children without any difficulty, 33% highly agreed and 8% neither agreed nor disagreed. the above results show that there was a positive effect on knowledge of parents after the CBR programme.

Figure 4: Frequencies Distribution of Changes in Knowledge of Parents about Cerebral Palsy



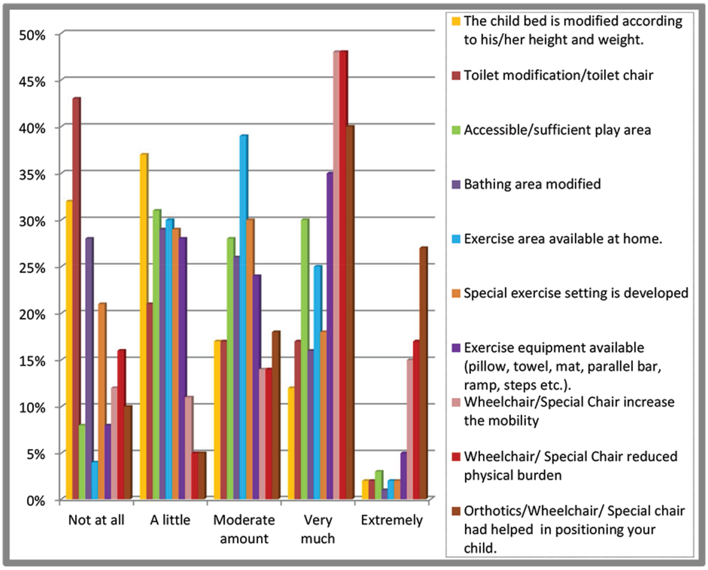
3. Social Life

While 60% agreed that the CBR programme made it easier to participate in social activities outside their homes, 27% highly agreed and 13% neither agreed nor disagreed with this. Sixty-eight percent (68%) of parents agreed that their family and society's attitude was positive after the implementation of the CBR programme, 25% highly agreed, 4% disagreed and 3% neither agreed nor disagreed. While 69% agreed that they do not feel neglected by the community members, 23% highly agreed, 5% neither agreed nor disagreed, 2% disagreed and 1% highly disagreed with this. Most of the respondents or 64% agreed that they get necessary time for their own needs and interest, 20% highly agreed, 11% neither agreed nor disagreed, 4% disagreed and only 1% highly disagreed in response to this. It was agreed by 61% of the study population that their social participation has increased (e.g., family gatherings, marriage, religious and social functions, etc.), 31% highly agreed, 6% neither agreed nor disagreed, and 2% disagreed. From these results it may be concluded that the CBR programme had a positive effect on the parents' social lives, although further improvement on this aspect is necessary.

4. Home Modification, Exercise Area and use of Assistive Devices

Among the children, the use of a wheelchair or a special chair increased mobility very much for 48%, extremely for 15% and moderately for 14%. Among the parents, the use of a wheelchair or special chair to transport their child had reduced the physical burden very much for 48%, extremely for 17%, and moderately for 14%. The use of orthotics, a wheelchair, or a special chair had helped in positioning their child very much for 40%, extremely for 27% and moderately for 18%. No major changes were found in home and toilet modifications for the children (Figure 5).

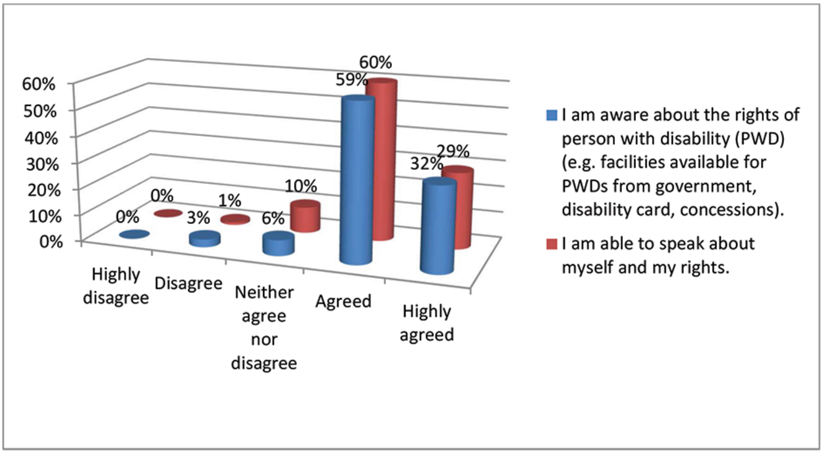
Figure 5: Distribution of changes in Home Modification, Exercise Area and use of Assistive Devices



5. Empowerment of Parents

Fifty-nine percent (59%) agreed that they are aware about the rights of people with disabilities (e.g. facilities available for people with disabilities from government, disability card, concessions). 32% highly agreed, six percent neither agreed nor disagreed and three percent disagreed to this question. 60% agreed that they are able to speak about themself and their rights. 29% highly agreed, 10% neither agreed nor disagreed and only one percent was disagreed to this question.

Figure 6: Empowerment of parents after CBR implementation.



II. Binary Logistic Regression

From the binary logistic regression, it was found that if knowledge changes from poor to good category, the health status increases by e^{β}unit, odds ratio $e^{\beta} = 4.096$.

It was also found that odds of good social life status are 6.14 times that of good health status, i.e., if the health status improves from poor to good, then social life improves by 6.14 times.

Odds of good social life status are 11.11 times that of good knowledge status. If knowledge changes from poor to good category, social life status will increase by 11 times.

Odds of the use of assistive device are 3.62 times that of GMFCS level. If GMFCS changes from IV to V category, use of assistive devices will increase by 3.62 times.

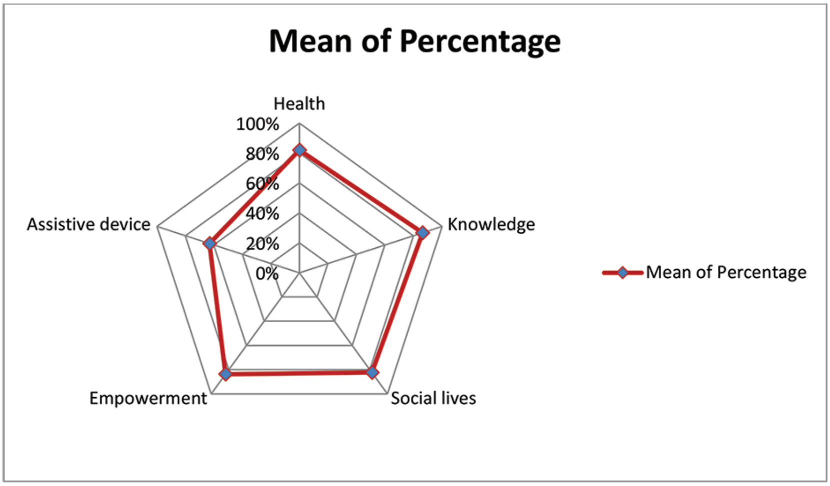
Table 4: Binary Logistic Regression between Domains

S.N	Domains			B	S.E	Wald	df	Sig.	Exp(B)
1.	Health vs. Knowledge	Step 1[a]	Knowledge(1)	1.414	.427	10.946	1	.001	4.111
			Constant	-2.317	.681	11.574	1	.001	.099

2.	Health vs. Social lives	Step 1[a]	Health	1.815	.485	14.008	1	.000	6.142
			Constant	-3.586	.821	19.077	1	.000	.028
3.	Knowledge vs. Social Lives	Step 1[a]	Knowledge	2.408	.552	18.996	1	.000	11.109
			Constant	-4.648	.984	22.299	1	.000	0.10
4.	GMFCS vs. Assistive device	Step 1[a]	GMFCS	1.288	.462	7.752	1	.005	3.624
			Constant	-5.358	2.162	6.139	1	.013	.005

III. Radar Graph

Figure 7: Radar Graph for Means of Health, Knowledge, Empowerment, Social Lives and Assistive Devices



Radar chart is a graphical way to compare data by displaying data in a "web-like" form. Since it resembles a spider web it is also known as a spider chart/graph. It is usually applied to evaluate multiple alternatives based on multiple criteria.

In the current study, the means of Health (82%), Knowledge (86.4%), Social Lives (82.32%), Empowerment (83.70%) and Assistive Device (63.08%) were put in the radar graph to draw a conclusion. Based on the Graph, it can be seen that Assistive

Devices has the lowest mean, which indicates that this area needs prioritisation in the near future, followed by Health of parents.

The reason for low effectiveness could be the lack of service, accessible houses and roads, and lack of awareness among the groups.

IV. Qualitative Results

Theme 1: Main Caregiver

Most of the respondents in this study were mothers (92%) and 8% were fathers. Usually, fathers are not as involved in taking care of a child as mothers. Many of the answers received were along these lines:

> *"I am a mother and it's my responsibility to take care of my child like other able children."*

There were also answers that stated the necessity of caring for a child with Cerebral Palsy and the effort required to do this due to presence of complications affecting almost all the major systems of the body. These complications make a child either partially or completely dependent on others for activities of daily living.

> *"I am taking care of my child because he is completely dependent and can't perform any activity of his own. And I am the only one to look after him."*

Parents are sincere well-wishers of their child. The parents in the study wanted their child to be happy and healthy, and to have a good future. Most of them also said that they wanted their child to be educated and become a good citizen of the country; hence, almost all the children were being sent to inclusive schools. No matter how hard it was, the parents were ready to do all that they possibly could.

> *"I am taking care of the child because he should improve physically and lead a happy life. I am also taking care of his education so that he can learn basic things and can spend quality time in school as well as with his friends."*
>
> *"We accept him as he is but we are worried about his future. We are trying to make him able up to possible extent so that in future he becomes less dependent on others."*

Theme 2: Challenges faced by Parents

The study uncovered various challenges experienced by parents in taking care of a child with special needs. The answers differed according to their locality and needs. In rural as well as urban areas the most challenging task was to find the right person for consultation. Parents said that it was really difficult for them to visit several doctors at different hospitals. Another problem was that they did not get the right rehabilitation guidelines to follow.

> *"Carrying her to different hospitals in public transport was difficult and the distance was very far from one hospital to another. After visiting various hospitals, we could not find the answers that we were looking for. Finally, one doctor suggested visiting APD; we came here and took appointment for rehabilitation. Now she has grown up and admitted to inclusive school within APD campus, here she gets rehabilitation as well as education. She uses wheelchair for mobility. I am here with her in school for whole day. I hardly get time for other things. Though the school is taking care of all the children, still being a mother, I cannot leave her alone."*

> *Apart from these challenges, some parents found it difficult to perform activities of daily living as the child was growing up.*

> *"Carrying the child outside for social gatherings and doing her exercise at home is very difficult as her hands and legs are so tight, and she feels pain and cries. No doubt we are getting parents' training but still it's really challenging to perform those exercises. I am giving my best to cope up with all the difficulties."*

In semi-urban and rural areas, the most common challenges were the use of assistive devices, access to education, and services available for these children; all caused by lack of accessibility. The durability of wheelchairs, orthotics, and other assistive devices was very inadequate due to uneven or rough roads. Most of the children are homebound because of poor accessibility both outside and inside the home.

> *"My child's name is registered in the school. Few days we took him to school but now we stop because we cannot carry him all the time as he is a grown-up child, and the wheelchair cannot move in this road. His class is in second floor and there is no ramp inside the school. Though we are getting facilities, yet we cannot utilise it due to various problems. Inside home this wheelchair is helping us a lot as he is sitting in proper position and plays with his brother and sisters and it also helps me in feeding his meals."*

Theme 3: Adjustments

The authors attempted to find out whether any "reasonable adjustments" were needed to help mothers, from their own point of view. Surprisingly, 98% said nothing was needed and claimed that they were happy with the on-going process of Community-Based Rehabilitation. Only 2% said that more frequent visits by the community worker would be a great help for them.

> *"We are happy with the service of APD in our community. It helps our children a lot; also, it helps me to perform his activities in an appropriate way. The parental training that we are getting at APD helps us to learn a lot about our own children and also, we can see the differences in our children's activity. The training I got helped me a lot to do exercise for my child and I am also aware of the benefits of doing exercises and using assistive devices. Before the training I was completely unaware about cerebral palsy, its complications and the uses of assistive devices. Thanks to APD for providing us such training and helping us to take care of our children."*

Theme 4: Training

Finally, respondents were asked whether training was needed specifically for mothers. The stated requirements were not very different from what was available in the ongoing training programmes. The mothers had benefited from these programmes and in future they expected training specific to their child's needs. They wanted to learn new skills and techniques so that they could do their best towards taking care of the child.

> *"I need training on specific exercise for my child because he is growing now and to cope with his physical growth, I need to learn new exercises based on his condition so that I can do for him at home."*

All the mothers were very active and willing to explore new treatment protocols which could help their child improve. They were very hopeful that training would help them in future with their growing child. Overall, there was good response from parents and their involvement in training showed their dedication towards their child's well-being.

DISCUSSION

Lang (2011) stated that organisations providing CBR services need to focus on awareness programmes related to disability and rehabilitation as well as vocational training for person with disability in order to achieve positive effectiveness of CBR services. The objective of this study was to identify the effects of the CBR programme on the lives of parents of children with Cerebral Palsy. CBR programmes are found to be effective not only for children with Cerebral Palsy but also for their parents, in various ways (Zuurmond et al, 2018). This study shows significant changes in parents' health, knowledge and social life, and also in community attitudes towards disability. The overall findings point to a good (positive) effect of CBR training programmes on parents' health, knowledge, social lives and their empowerment.

Family and society attitude towards mothers of children with Cerebral Palsy improved. As a result of continuous awareness raising as part of the CBR programme mothers indicate that they have sufficient time to participate in social activities and do not feel neglected. Training of mothers or parents not only helps in children's interventions but also reduces the physical and mental burden on parents. Use of assistive devices is helpful for both children with Cerebral Palsy and their parents as it helps in the positioning and mobility of the child and reduces the burden of carrying the child outside. Though CBR programmes are providing rehabilitation along with the assistive devices, it is often difficult to use the available assistive devices due to poor accessibility of the environment outside their home such as in various schools.

Significant associations were found between the various areas of CBR. The odds among them were more than 3, therefore it can be said that training parents is highly effective in terms of inclusion, rehabilitation and achieving the intended goal of rehabilitation.

Apart from the positive effect on the child, CBR programmes have a positive impact on parents' overall activity. The radar graph shows that priority should be given to the provision of assistive devices as it was the least benefited area among all the variables. The reasons could be lack of accessibility within and outside the home, lack of service, and lack of awareness among the groups. It could be assumed that if accessibility of the internal and external environment improves, the uses and service of assistive devices will increase, and this would have a positive effect on both children with Cerebral Palsy and their parents (Copley & Ziviani; 2004; Mihaylov et al, 2004).Based on the qualitative findings, more hands-on training should be provided to parents so that they would be better equipped to care for their children as they grow older. It is really difficult to find professionals in the rural community to provide rehabilitation to Cerebral

Palsy children on a day-to- day basis (Bunning et al, 2014); therefore, training of parents is required. Training parents along with teachers could be of added benefit. Counselling of school staff is also needed in order to achieve inclusion in schools. To further this, grassroots workers and community facilitators need to work together, and training and continuous support to the group is a must (Barth, 2009).

CONCLUSION

The study results demonstrate that CBR programmes have a positive effect on parents' health, knowledge, social lives and empowerment. The odds ratios between them are greater than 1 and show that CBR programmes are very effective for parents and children with Cerebral Palsy. To make them even more effective, different service provisions under the CBR programme are needed at community level as well.

It is recommended that further studies should be done to gauge the effectiveness of each parents' training programme in the community centres. This could help the CBR training provider to know how much parents have learnt, to what extent they are putting it into practice and whether any improved method or new training item should be included in the training programme.

To get a clearer picture about the effectiveness of the programmes, further studies must include those organisations and NGOs that are working along CBR lines.

A study that focuses on the challenges experienced by grassroots workers in implementing or providing service in rural communities is also recommended.

The study results can help CBR programmes to identify groups of persons (parents) who benefit less from specific activities, and thereafter develop and adopt strategies to improve their participation. It could be useful in the further development of CBR programmes to place more emphasis on the training of parents of children with disabilities.

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Activity Limitation of People Affected by Leprosy in an Endemic District in West Bengal, India

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ABSTRACT

Purpose: *This study aimed to assess the level of activity limitation, and the factors associated with it, among people affected by leprosy who were reporting at a leprosy referral centre of Purulia, in West Bengal state, India.*

Method: *A cross-sectional study was conducted among 358 individuals affected by leprosy. Persons recruited for this study were above 18 years of age, married, and had been diagnosed with leprosy for at least 1 year at the time of the interview. A semi-structured questionnaire was used to gather information about the respondents' socio-economic and disease status. The Screening of Activity Limitation and Safety Awareness (SALSA) Scale was used to measure activity limitation.*

Results: *Of the 358 respondents, 59% were male, 60% were between 18 and 45 years of age, and 42% were illiterate. About 144 or 40% of the respondents had Grade 2 disability and 60% had disease duration of more than 3 years. There were 229 individuals (64%) who had no limitation in activities, 103 (29%) had mild limitation and 26 (7%) had moderate to severe limitation in activities. There is a significant association between gender, age, occupation, physical disability and disease duration with activity limitation.*

Conclusion: *It appears that limitations in activities among persons affected by leprosy are associated with being a woman, a housewife, an aged person, and with longer disease duration. The physical disability was intrinsically associated with limitation in activities.*

Key words: *leprosy, activity limitation, disability, India*

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INTRODUCTION

Leprosy is a chronic infectious disease caused by *Mycobacterium leprae* and it affects the skin and peripheral nervous system (World Health Organisation, 2010). Disabilities in leprosy are mainly due to damage to peripheral nerves (Britton and Lockwood, 2004; Vijayan and Wilder-Smith, 2016; Rathod et al, 2020). Nerve damage can occur as part of lepra reaction with signs of acute inflammation. Damage to the nerves results in impairment of sensory, motor and autonomic functions, leading to anaesthesia, paralysis of muscles in eyes and extremities, loss of sweating and fissures or cracks or ulcers over extremities. These impairments can worsen over time if they are not recognised and the necessary interventions taken (Darlong et al, 2017). Early detection and treatment of nerve function impairment would prevent the occurrence of disability (Nicholls et al, 2003; Van Veen et al, 2006; Van Brakel and Officer, 2008; Ramasamy et al, 2019).

Several dimensions of disability are recognised in the International Classification of Functioning, Disability and Health (ICF), namely, body structure (impairment), activity (activity limitations) and participation (participation restrictions). Impairment is a problem in body function or structure (WHO, 2001). An activity limitation is a difficulty, encountered by an individual in executing a task or action, while a participation restriction is a problem experienced by an individual in involvement in life situations. The classification also recognises the role of physical and social environmental factors in affecting disability outcome (Van Brakel et al, 2012). Moreover, disabilities due to leprosy affect limitation in activities of an affected individual (De Souza et al, 2016).

Aim

Hence, this study aimed to assess the level of activity limitation and to study the factors associated with activity limitation of people affected by leprosy who were reporting at a leprosy referral centre of Purulia, in West Bengal state, India.

METHOD

Study Design

A cross-sectional descriptive study was conducted with 358 individuals affected by leprosy.

Study Setting

The participants were recruited from among those who attended the leprosy referral outpatient department of a tertiary hospital in Purulia district, of West Bengal state in Eastern India, from April to June 2017.

Sample Size

Records of adult clients (18 years of age and above) who had visited the hospital over the last 5 years were extracted from the registration database of the study institute. On an average, 3430 clients had visited every year for treatment, and this number was rounded off to 3500 to determine the sample size. The actual sample size for the study was determined by using open source epidemiologic statistics for public health (Dean et al, 2013), by assuming 5% marginal error, 95% confidence interval (alpha=0.05), and the proportion of 50%. Results showed that the required sample size for the study was 347 respondents.

Participants

The inclusion criteria:

- People diagnosed with leprosy for at least 1 year at the time of interview;
- Above 18 years of age and married;
- Willing to participate and give informed consent.

The exclusion criteria:

- People not capable of independent communication.

Data Collection

Semi-structured Questionnaire - A semi-structured questionnaire was prepared to collect the demographic profile and disease profile of people affected by leprosy. The demographic profile included information on gender, age, education, occupation, family income, and family size. The disease profile included disease duration and disability grade. The level of disability was measured by the World Health Organisation (WHO) disability grade system which grades clients with leprosy according to disabilities of the eyes, hands and feet (Brandsma and Van Brakel, 2003).

Screening of Activity Limitation and Safety Awareness Scale (SALSA Scale)

The SALSA is a questionnaire that measures activity limitation and risk awareness in peripheral neuropathy mainly due to leprosy and diabetes. The SALSA Scale was developed and tested in six languages - Chinese (Mandarin), English, Hausa, Hebrew, Portuguese (Brazilian), Tamil - by the SALSA Collaborative Study Group (2007). It is a cross-cultural tool, comprising 20 items related to three domains - mobility, self-care and work. It is a subjective tool, placing the interviewees at the centre and presenting how the clients perceive their functional level. Each item of the SALSA Scale ranges from '0' to '4' (0 - 'I do not do this activity', 1 - 'The activity is easy to carry out', 2 - 'The activity is a little difficult to carry out', 3 - 'The activity is very difficult to carry out', and 4 - 'I physically cannot do the activity' or 'I avoid the activity because of risk').

The scores range from '0' (minimum) to '80' (maximum) points. People with scores ranging from 10 to 24 are considered to experience no limitation in activities; those with scores from 25 to 39 are with mild limitation; 40 to 49 with moderate limitation; 50 to 59 with severe limitation; and 60 to 80 with extreme limitation.

In this study, the Bengali translation of the SALSA Scale was used to measure the level of activity limitation (SALSA Scale Bengali). The Bengali version of the SALSA Scale was translated and validated (face and content validity) by the SALSA Scale development group. However, the study group has not tested the reliability.

Construct Validity - The Bengali version Participation Scale (P Scale) (Van Brakel et al, 2006) and the World Health Organisation Quality of Life (WHOQOL-BREF) Scale (WHOQOL Group, 1998; Tsutsumi et al, 2006) were used to establish the construct validity of the Bengali version of the SALSA Scale. The P Scale and WHOQOL-Bref were used to measure the social participation restriction and quality of life of people affected by leprosy, respectively. The researcher hypothesised that activity limitation of the people affected by leprosy would be positively correlated with the P Scale and inversely correlated with WHOQOL-Bref.

Reliability - In this study, the internal consistency was used to test the reliability of the Bengali version of the SALSA Scale. Internal consistency is considered good if alpha ranges between 0.70 and 0.90 (Cardol et al, 2001).

Procedure

The first author was assigned to recruit participants, describe the study to them and obtain informed written consent. The first author performed the interview with the assistance of three trained field investigators.

The interview consisted of gathering information about present demographic and disease status followed by administration of the SALSA Scale, P Scale and WHOQOL-BREF Scale. All interviews were conducted in the local language – Bengali - and in strict privacy after building rapport with the respondents. Interviews lasted from 30 to 45 minutes. At any sign of emotional distress, the interview could be terminated; however there was no occasion to do so.

Data Analysis

The data was entered in the Microsoft Excel database and analysed using SPSS. The descriptive statistics and Chi-square test were done to compare the groups. Independent ‘t’ test was done for the items to observe the difference between males and females. Reliability analysis was performed for 20 items of the SALSA Scales. Pearson correlation analysis was performed for construct validity. P-values less than 0.05 were regarded as statistically significant.

Ethical Considerations

The study was approved by the Doctoral Research Committee members of the Department of Sociology, Bharathidasan University, and the Research Ethics Committee of The Leprosy Mission Trust India. The participation of respondents in the study was voluntary and information was collected anonymously after obtaining written consent from each of them. Confidentiality was maintained throughout the data collection period.

RESULTS

Details of the respondents’ demographic profiles, disability status and disease duration are described in Table 1. Of the 358 respondents, 59% were male and 41% were female. Most of them (214 or 60%) were between 18-45 years of age, 42% were illiterate and 55% had occupations such as labourer and farmer. About 47% of the respondents were living in medium-sized families (5 to 8 members) and 75% of their monthly family income was below Rs.5000 (Indian currency). Visible impairments (WHO Grade 2) were present among 144 (40%) of the respondents and 60 % of them were diagnosed more than 3 years ago.

Table 1: Demographic Profile, Disability Status and Disease Duration of the Respondents (n=358)

Status	Frequency	Percent
Gender		
Male	212	59.2
Female	146	40.8
Age		
18-30 years	69	19.3%
31-45 years	145	40.5%
46-60 years	111	31.0%
Above 60 years	33	9.2%
Education		
Illiterate	207	57.8
Literate	151	42.2
Occupation		
Labourer	99	27.7
Farmer	96	26.8
Housewife	135	37.7
Others (Professional & Business)	28	7.8
Family Size		
Small Family (4 members)	128	35.8
Medium Family (8 members)	167	46.6
Large Family (>8 members)	63	17.6
Family Income		
Below Rs.5,000	270	75.4
Above Rs.5,000	88	24.6
WHO Disability Grade		
Grade 0	150	41.9
Grade 1	64	17.9
Grade 2	144	40.2
Disease Duration		
1 to 3 years	144	40.2
3 to 5 years	112	31.3
Above 5 years	102	28.5

Internal Consistency

The results showed that the reliability coefficient (Cronbach's alpha) was 0.891. Corrected item-total correlation ranged from 0.880 to 0.897, with all the 20 items falling at or above 0.880 (shown in Table 2). The Bengali version of the SALSA Scale has been shown to have very good internal consistency and reliability.

Table 2: Descriptive Statistics of the Items of the SALSA (range per item 0-4) and Corrected Item-Total Correlation (n=358)

	Items	Mean	Std. Deviation	Corrected Item- Total Correlation	Cronbach's Alpha if Item Deleted
1	Can you see (enough to carry out your daily activities)?	1.3352	.53916	.048	.897
2	Do you sit or squat on the ground?	1.4078	.70305	.396	.890
3	Do you walk barefoot? (e.g. most of the time)	1.5475	.87718	.347	.893
4	Do you walk on uneven ground?	1.6844	.87820	.446	.889
5	Do you walk longer distances? (i.e. longer than 30 minutes)	1.6816	.85945	.440	.889
6	Do you wash your whole body? (using soap, sponge, jug; standing or sitting)	1.1369	.43092	.538	.887
7	Do you cut your finger or toenails? (e.g. using scissors or clippers)	1.1704	.53611	.570	.885
8	Do you hold a cup or basin with hot contents? (e.g. drinks, food)	1.2318	.63457	.620	.883
9	Do you work with tools? (i.e. tools which you hold in your hands to help you work)	.9749	.78995	.290	.894

10	Do you carry heavy objects or bags? (e.g. shopping, food, water, wood)	1.3631	.75740	.645	.882
11	Do you lift objects above your head? (e.g. to place on a shelf, on your head, to hang clothes to dry)	1.1676	.89183	.585	.884
12	Do you cook? (i.e. prepare food both hot and cold)	.7709	.75448	.273	.894
13	Do you pour hot liquids?	1.0391	.73613	.452	.888
14	Do you open/close screw capped bottles? (e.g. oil, water)	1.2179	.67572	.743	.880
15	Do you open jars with screw-on lids? (e.g. jam)	1.2402	.68054	.725	.880
16	Do you handle or manipulate small objects? (e.g. coins, nails, small screws, grains and seeds)	1.2179	.61495	.757	.880
17	Do you use buttons? (e.g. buttons on clothing, bags)	1.1788	.60935	.749	.880
18	Do you thread needles? (i.e. pass thread through the eye of a needle)	1.0978	.79490	.501	.887
19	Do you pick up pieces of paper, handle paper or put it in order?	1.1760	.58915	.727	.881
20	Do you pick up things from the floor?	1.1872	.59045	.685	.882

Construct Validity

The total score of the SALSA Scale had a moderate positive correlation with the P Scale (r = 0.402, p=0.000) and a moderate negative correlation with WHOQOL total score (r = -0.507, p=0.000).

Activity Limitation

Among the 358 respondents, 229 (64%) had no limitation in activities, 103 (29%) had mild limitation and 26 (7%) had moderate to severe limitation in activities (shown in Table 3).

Table 3: Level of Activity Limitation Measured by SALSA Scale (n=358)

Activity Limitation	Frequency (n)	Percent (%)
No limitation (0-24)	229	64.0%
Mild limitation (25-39)	103	28.8%
Moderate limitation (40-49)	17	4.7%
Severe limitation (60-80)	9	2.5%

Association between Variables and Activity Limitation

To understand the association between activity limitation and other variables, data was dichotomised based on the SALSA Scale score - scores of 24 or less were described as 'no activity limitation' and above 24 as 'activity limitation' (shown in Table 4). The results showed that there is no association between education and family income with activity limitation. However, gender, occupation, disability grade and disease duration of the respondents showed a highly significant association with activity limitation.

Table 4:Association between Variables and Activity Limitation (n=358)

	Activity Limitation					
Status	No Activity Limitation n = 229		Activity Limitation n = 129		Total n = 358	p-value
Gender						
Male	150	71%	62	29%	212	<0.01
Female	79	54%	67	46%	146	

Age						
18-30 years	55	80%	14	20%	69	<0.05
31-45 years	89	61%	56	39%	145	
46-60 years	65	59%	46	41%	111	
Above 60 years	20	61%	13	39%	33	
Education						
Illiterate	125	60%	82	40%	207	.099
Literate	104	69%	47	31%	151	
Occupation						
Labourer	73	74%	26	26%	99	<0.01
Farmer	67	70%	29	30%	96	
Housewife	70	52%	65	48%	135	
Others	19	68%	9	32%	28	
Family Income						
Below Rs. 5000	168	62%	102	38%	270	.229
Above Rs. 5000	61	69%	27	31%	88	
Disability Grade						
Grade 0	126	84%	24	16%	150	<0.01
Grade 1	45	70%	19	30%	64	
Grade 2	58	40%	86	60%	144	
Disease Duration						
1 to 3 years	107	74%	37	26%	144	<0.01
3 to 5 years	67	60%	45	40%	112	
Above 5 years	55	54%	47	46%	102	

The multivariate Chi-square distribution was done to observe the activity limitation by gender (shown in Table 5), age (shown in Table 6), occupation (shown in Table 7) and disease duration (shown in Table 8), with disability grade. The results showed that there is an association observed among the disability grade ‘0’ and grade ‘1’ group between gender and activity limitation (shown in Table 5). Among the disability grade ‘1’ group, there is an association observed between occupation and activity limitation (shown in Table 7).

Table 5: Activity Limitation by Gender and Disability Grade of the Respondents (n=358)

Disability Grade	Gender	Activity Limitation				Total	p-value
		No		Yes			
Grade 0	Male	76	89%	9	11%	85	<0.05
	Female	50	77%	15	23%	65	
	Total	126	84%	24	16%	150	
Grade 1	Male	34	92%	3	8%	37	<0.01
	Female	11	41%	16	59%	27	
	Total	45	70%	19	30%	64	
Grade 2	Male	40	44%	50	56%	90	0.188
	Female	18	33%	36	67%	54	
	Total	58	40%	86	60%	144	

Table 6: Activity Limitation by Age and Disability Grade of the Respondents (n=358)

Disability Grade	Age	Activity Limitation				Total	P-value
		No		Yes			
Grade 0	18-30 years	43	91%	4	9%	47	0.124
	31-45 years	49	77%	15	23%	64	
	46-60 years	28	85%	5	15%	33	
	Above 60 years	6	100%	0	0%	6	
	Total	126	84%	24	16%	150	
Grade 1	18-30 years	5	71%	2	29%	7	0.945
	31-45 years	19	70%	8	30%	27	
	46-60 years	14	67%	7	33%	21	
	Above 60 years	7	78%	2	22%	9	
	Total	45	70%	19	30%	64	
Grade 2	18-30 years	7	47%	8	53%	15	0.958
	31-45 years	21	39%	33	61%	54	
	46-60 years	23	40%	34	60%	57	
	Above 60 years	7	39%	11	61%	18	
	Total	58	40%	86	60%	144	

Table 7: Activity Limitation by Occupation and Disability Grade of the Respondents (n=358)

Disability Grade	Occupation	Activity Limitation				Total	p-value
		No		Yes			
Grade 0	Labourer	42	89%	5	11%	47	0.076
	Farmer	28	93%	2	7%	30	
	Housewife	44	75%	15	25%	59	
	Others	12	86%	2	14%	14	
	Total	126	84%	24	16%	150	
Grade 1	Labourer	15	83%	3	17%	18	<0.01
	Farmer	17	100%	0	0%	17	
	Housewife	9	36%	16	64%	25	
	Others	4	100%	0	0%	4	
	Total	45	70%	19	30%	64	
Grade 2	Labourer	16	47%	18	53%	34	0.467
	Farmer	22	45%	27	55%	49	
	Housewife	17	33%	34	67%	51	
	Others	3	30%	7	70%	10	
	Total	58	40%	86	60%	144	

Significance Test between Gender and Activity Limitation

The significance test was done for the individual item between gender and activity limitation and significant difference observed in item-4 (walk on uneven ground), item-5 (walk longer distance), item-9 (work with tools), item-11 (lift objects above head), item-12 (cook), item-13 (pour hot liquids) and item-18 (thread needle).

The results showed that the female respondents had slightly higher limitation than male respondents in activities such as walking on uneven ground, walking longer distance, lifting objects above head, cooking, pouring hot liquids and threading a needle. The male respondents in turn had slightly higher limitation in working with tools than the female respondents.

Table 8: Activity Limitation by Disease Duration and Disability Grade of the Respondents (n=358)

Disability Grade	Disease Duration	Activity Limitation				Total	p-value
		No		Yes			
Grade 0	1 to 3 years	66	84%	13	16%	79	0.984
	3 to 5 years	39	85%	7	15%	46	
	Above 5 years	21	84%	4	16%	25	
	Total	126	84%	24	16%	150	
Grade 1	1 to 3 years	26	74%	9	26%	35	0.157
	3 to 5 years	7	50%	7	50%	14	
	Above 5 years	12	80%	3	20%	15	
	Total	45	70%	19	30%	64	
Grade 2	1 to 3 years	15	50%	15	50%	30	0.412
	3 to 5 years	21	40%	31	60%	52	
	Above 5 years	22	35%	40	65%	62	
	Total	58	40%	86	60%	144	

DISCUSSION

Leprosy-related disability is a challenge to public health. Disability is more than a mere physical dysfunction as it includes activity limitations, stigma, discrimination, and social participation restrictions. Globally, the new cases with grade 2 disability numbered more than 10000 in 2014-2018 and 11323 cases were registered in the year 2018 (WHO, 2019). In India, 3666 new cases with grade 2 disability were reported in the year 2018 (WHO, 2019). The current study revealed the level of activity limitation and the factors associated with activity limitation of people affected by leprosy.

In the present study, about two-thirds of the participants (64%) had reported no activity limitation whereas one-third of them (36%) experienced some limitation in activity. Among those with activity limitation, 7% had moderate to severe limitation in activities. The proportion of people with limitation in activities was lower in this study than the 58% found in the study by Nardi et al (2012) and the 67% in the study by De Souza et al (2016) in Brazil, and the 60% found in the study in Indonesia by Van Brakel et al (2012).

In the current study, more females (46%) than males (29%) experienced activity limitation and the reason may be that females are mainly engaged in household work. Findings of this study are consistent with the findings of the study conducted in Brazil (Nardi et al, 2012) and Indonesia (Van Brakel et al, 2012). On the contrary, another similar study from Brazil (Santos et al, 2015) found that there was no difference in activity limitation among the males and females.

Older persons affected by leprosy suffered more limitation in activities when compared to younger persons; this was consistent with the findings of the study conducted in Brazil (Nardi et al, 2012). The activity limitation among literate and illiterate respondents was not influenced by the educational status. However, the Brazilian study found that limitation of activities was experienced by those who had less than 6 years of schooling, compared to those who attended school for longer periods (Nardi et al, 2012).

The study by Nardi et al (2012) in Brazil, found that people affected by leprosy and with low-risk occupations (activities or occupations that do not require intense or constant effort or repetitive movements for most of the day) had reported higher limitation in activities, and people with low incomes had reported higher limitation in activities when compared to those with higher incomes. The present study found that homemakers experienced higher limitation in activities. It is interesting to observe that respondents from the low family-income group as well as from the high-income group experienced the same level of activity limitation.

Studies from India suggest that physical disabilities do affect the quality of life (Govindharaj et al, 2018) and social participation (Ramasamy et al, 2018; Govindharaj et al, 2019; Ramasamy et al, 2019) of people affected by leprosy. The present study demonstrated that people who had visible impairments (grade 2 disability - 60%), experienced more activity limitation compared to those respondents who had only loss of sensation (grade 1 - 30%). Studies from Philippines (Boku et al, 2010), Indonesia (Van Brakel et al, 2012), Brazil (Nardi et al, 2012; Santos et al, 2015) and India (Kamble et al,2012) also reported similar findings.

Furthermore, the study observed that the activity limitation was greater among persons who had a longer history of disease duration. This study shows that the females with disability (grade 0 and grade 1) had more limitation in activities than the males.

The internal consistency of the SALSA Scale was good and the Cronbach alpha was 0·96. The construct validity of the SALSA was supported by the moderately positive correlation with the P-Scale and moderately negative correlation with the WHOQOL-BREF. The SALSA Scale is reliable and valid to measure activity limitation in people affected by leprosy.

Limitations

The study assessed the activity limitation among people affected by leprosy with a large-sized sample. However, there are some limitations. Due to resource and time constraints, this was conducted as a cross-sectional study in a tertiary leprosy referral centre and the study has not been retested. Future studies will need to investigate the SALSA Scale test-retest reliability and to validate the Scale. Further comparative and intervention studies need to be undertaken on activity limitation among people affected by leprosy.

CONCLUSION

This study shows that the SALSA Scale is an easy tool to measure the activity limitations among people affected by leprosy. Activity limitations of people affected by leprosy are associated with being a woman, a housewife, an aged person and with longer disease duration. The physical disability was intrinsically associated with activity limitations. Multidisciplinary rehabilitation approaches may help to improve the activities of daily living among people affected by leprosy and also improve their quality of life.

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Disclosure of Disease among Women affected by Leprosy: A Qualitative Study

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ABSTRACT

Purpose: *Although leprosy is completely curable with multidrug therapy, it is unfortunate that the stigma attached to leprosy persists even today. Fear of social exclusion prevents disclosure of the disease to the family and community. This study aimed to evaluate the extent of disclosure of disease among women affected by leprosy in a tertiary referral hospital in Chhattisgarh State, India.*

Method: *A qualitative study was conducted with 57 women affected by leprosy who reported at a tertiary referral hospital in Champa, Chhattisgarh State. The respondents were 18 years of age or older, and had completed multidrug therapy for leprosy. They were asked whether the disclosure of disease had affected their interactions with family, neighbours and community members.*

Results: *Of the 57 women, 48 (84%) had disclosed their disease to their family, 17 (30%) to their neighbours and 13 (23%) to the community members. Thirty women (53%) reported that they experienced problems after revealing the ailment to their family, friends and neighbours. The qualitative analysis found that negative behaviour towards people affected by leprosy still persists in the community. Consequently, women affected by leprosy try to hide their disease due to fear of negative community reactions.*

Conclusion: *This study emphasises the need to spread awareness about the disease and its transmission, by educating the people affected by leprosy, their families and the community. This should be a continuous process in order to reduce or remove the stigma and discrimination against women affected by leprosy, in particular.*

Key words: *leprosy, disclosure, women, stigma, Champa*

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INTRODUCTION

Today leprosy is curable with multidrug therapy (MDT) (WHO study group, 1982). Unfortunately, the stigma attached to leprosy still persists (Kaur and Ramesh, 1994; Scott, 2000) and it remains a problem in several countries, particularly in India (Noriega et al, 2016). Society maintains negative feelings toward people with leprosy (Singh, 2012). Perception of stigma and experiences of discrimination cause people to feel ashamed, and may lead them to isolate themselves from society, thus perpetuating the stereotype that leprosy is something shameful to be hidden (Arole et al, 2002). This may cause anxiety, depression, isolation, problems in family relationships and friendships, also in reduced treatment adherence and retaining responsibilities in family life. In communities of many developing countries, the real situation of people affected by leprosy is often characterised by extreme dependency and discrimination in every aspect of their lives (Rao et al, 1996).

Women with leprosy encounter many problems in daily life, mainly due to stigma (Sarkar and Pradhan, 2016). Women with disabilities are often beaten or abused (Disabled World, 2018). Peters et al (2014) observed that the women who had concealed their illnesses were the ones who most frequently reported feelings of fear, sadness, shame, low self-esteem and depression, and that these feelings often resulted in self-isolation. Besides, women affected by leprosy experience more fear of the disease than the men affected by leprosy (Govindharaj et al, 2018). Out of fear of infecting family members, affected women keep themselves aloof and are constantly worried about their marriage prospects or, if married, about divorce and separation. Fear of social ostracism prevents them from disclosure of the disease to the community (Kaur and Ramesh, 1994). The major cause for late diagnosis of leprosy in women is the fear of stigma and being ostracized by family and community (Varkevisser et al, 2009).

Aim

This study aimed to evaluate the challenges regarding disclosure of disease among the women affected by leprosy in a tertiary referral hospital at Champa in Chhattisgarh State, India.

METHOD

Study Setting

A qualitative study was conducted from March to June 2016 at a tertiary leprosy referral hospital in Champa, Chhattisgarh State.

Study Sample

The participants were 57 women, aged 18 years and above, who had completed their multi-drug therapy (MDT). Informed consent was obtained from each individual and the interview was conducted in privacy. Confidentiality was maintained throughout the study.

Study Tool

A semi-structured questionnaire was used to record the demographic and disease profile of the women. They were asked questions about disclosure of their disease in order to know whether the disclosure affects their participation among family, neighbours and community members.

Ethics Approval

The study proposal was approved by the Allagappa University, in Tamil Nadu, India.

Permission to conduct the study was obtained from the superintendent of Bethesda Leprosy Mission Hospital.

RESULTS

Demographic Profile

Of the 57 women, 20 (35%) were between 18 and 30 years of age, 88% were married and 51% were illiterate. Nearly half of them (45%) were housewives and 84% had family income below Rs 5000 (Indian currency) (shown in Table1).

Table 1: Demographic Profile of the Participants (n=57)

Variables	Frequency	Percent (%)
Age		
18 – 30	20	35%
31 – 60	37	65%
Marital Status		
Married	50	88%
Single	7	12%
Education		
Primary & Secondary	20	35%
Higher Secondary & above	8	14%
Illiterate	29	51%
Occupation		
Housewife	26	45%
Farmer	11	19%
Labourer	14	25%
Student	6	11%
Family Income per month		
Up to Rs.5000	48	84%
Above Rs.5000	9	16%

Disease Profile

About three-fourths (74%) of the affected women were diagnosed as multibacillary disease and 23% had grade 2 disability. Nearly half of them (44%) had been released from treatment (RFT) for more than 2 years, and 30% came to the hospital for illness due to leprosy (shown in Table 2).

Table 2: Disease Profile of the Participants (n=57)

Variables	Frequency	Percent (%)
WHO Classification		
Multibacillary (MB)	42	74%
Paucibacillary (PB)	15	26%
WHO Disability Grade		
Grade 0	32	56%
Grade 1	12	21%
Grade 2	13	23%
Release From Treatment (RFT)		

0- 2 years	32	56%
3- 4 years	15	26%
Above 4 years	10	18%
Reason for visit to Hospital		
Follow-up	25	44%
Leprosy Complaint	17	30%
Non-Leprosy Complaint	15	26%

Disclosure of Disease

Among the 57 participants, 48 (84%) had disclosed their disease to their family, 17 (30%) had disclosed it to their neighbours and 13 (23%) had disclosed it to the community members (shown in Table 3).

Table 3: Disclosure of Disease by the Participants (n=57)

Disclosure of Disease	Frequency	Percent (%)
Family		
Disclosed	48	84%
Not Disclosed	9	16%
Neighbours		
Disclosed	17	30%
Not Disclosed	40	70%
Community		
Disclosed	13	23%
Not Disclosed	44	77%

Factors affecting Disclosure of Disease

The findings that were identified and emerged through analysis of qualitative data concerning disclosure of disease were: fear of disease, positive experience after disclosure, violent reaction after disclosure, psychological issues, self-stigma, problems in practicing self-care, stigmatisation and family members, beliefs and myths attached to leprosy, experience of social stigma, and employment issues.

a) Fear of the disease

An 18-year-old female college student who had a claw hand deformity said,

> *"I feel afraid if my friends come to know, they will gossip about my health condition and ignore me; also, I lack interest in my studies."*

b) Positive experience after disclosure

Twenty-seven (27) women (47%) reported that they did not have any problem due to the disease and also that there was no discrimination and stigmatising attitude in their village. A 39-year-old woman reported that people already knew that she was affected by leprosy because of her hospitalisation. However, she did not face any stigmatising attitude from people in her village.

A few women had made the disclosure themselves, while a few were identified by others due to their visible physical deformities. A 27-year-old woman had completed her MDT 10 years earlier. She had developed self-confidence after completing her treatment and was ready to face any problems which might arise due to leprosy.

A 48-year-old woman without a physical disability, who was treated 6 years previously, said,

> *"In my village, all the community members are aware that I have been treated for leprosy, but still there wasn't any problem with me. I as usual participate in all the social activities and my neighbours come to my home just like before."*

Another 35-year-old woman without a physical disability, who was treated 2 years earlier, said,

> *"In my village all of them know I was affected by leprosy, and we are all living together without any problem."*

A 30-year-old woman with an ulcer on her right foot said,

> *"Due to ulcer on my foot, most of my neighbours know I was affected by leprosy, but they never neglected me. I myself feel inferior and avoid participating in social activities and functions in my village."*

c) Violent reaction after disclosure

Women affected by leprosy are sometimes abandoned by their husbands. In this study, a

41-year-old woman who had no disability and was treated 10 years earlier said,

> *"My husband called me as a leper and abused me whenever he had alcohol. He even rejected and did not support me get treatment in the early disease period (early stages of the disease)."*

d) Psychological issues

One 32-year-old woman did not disclose the disease to anyone but felt ashamed and isolated herself.

Another 33-year-old woman said,

> *"I was very upset and depressed and had suicidal thoughts many times due to this disease. Nowadays I get unnecessarily stressed and afraid to tell anyone."*

A 40-year-old woman who underwent treatment 5 years ago said,

> *"Due to the visibility of patches on my face and hand, all of them came to know I was affected with leprosy. But myself getting angry and frustrated to live, asked myself, Why me? What sin have I committed?"*

e) Self-stigma

A 53-year-old woman said that some people affected by leprosy are already living in the same village. When looking for a bride for her son, her family was not willing to find someone from the general community because of fear of stigma and discrimination. For this reason, preference was given to a family with a history of leprosy.

Another woman, 50years of age, who was treated for leprosy 6 years earlier, said,

> *"By God's grace, I have only patches in my body which are not visible to others. If I had any signs and physical deformities, people may easily identify and discriminate me."*

f) Problems in practicing self-care

A 35-year-old woman had anaesthetic foot and used to avoid using micro-cellular rubber (MCR) footwear in her village due to fear of stigma and discrimination.

Another 50-year-oldwoman with anaesthetic foot, living in a joint family, disclosed her health status only to her husband and children, but the rest of the family members were not aware of it. If they had known that she was affected by leprosy, there were chances that her family would be isolated from the other family members. Hence, she avoided wearing MCR footwear.

g) Stigmatisation and family members

A 27-year-old woman who had recently completed treatment said that she always came with her father to collect medicines. She had not disclosed the disease status to her husband and in-laws due to fear of divorce. Another 25-year-old woman also revealed that she never wanted to disclose her health status to her husband and in-laws for fear of divorce. She could not imagine herself as a divorced woman, so only her parents knew about her health condition.

h) Beliefs and myths attached to leprosy

A 52-year-old woman, who had received MDT ten years previously, believed that if her enemies came to know that she had been affected by leprosy, they could easily send evil spirits towards her and her family.

i) Experience of societal stigma

A 32-year-old woman, treated for leprosy 10 years before her marriage, said,

> *"When I started to come to the hospital for leprosy care, I came to know that there are some people from my village who are already affected with leprosy, and so the community members have separated and sent them to the nearby leprosy colonies, so I started to hide about my health condition to my husband and my in-laws."*

A 30-year-old married woman, who had been given MDT two years earlier, said,

> *"Only my husband knows about my disease status and I fear to disclose it to my remaining family members, because I had an experience in my village about 10 years ago. There was an old lady diagnosed with leprosy, so the community members isolated her in a nearby farm; after a few months the lady died, without any help from others."*

A 32-year-old woman, treated with MDT two years previously, experienced stigmatization from the community in her village. People identified that she was affected with leprosy by the visible skin patches on her body. Whenever she used to go to bath in the pond, people used to keep a safe distance and gossip about her among themselves.

j) Employment issues

A 31-year-old woman was a Panchayat member in her village. She had completed MDT about 3 years earlier but feared disqualification from her post if community members should come to know that she had been affected by leprosy.

DISCUSSION

This study attempted to identify the factors affecting disclosure of disease among women affected by leprosy. The study observed that 30 women (53%) had problems resulting from disclosure of the disease to their family, friends and neighbours.

The fear of leprosy leads to stigma and discrimination. This is due to lack of understanding and knowledge about leprosy, which increases misconceptions about the disease transmission and treatment (Navon, 1998). Fear of social ostracism prevents the disclosure of disease to the spouse, family members, relatives or friends (Thilakavathi et al, 2012) and also to the community (Kaur and Ramesh, 1994). In this study, nine (16%) of the participants did not disclose the disease status to their family due to fear of stigmatisation, and forty (70%) of them did not disclose the disease status to their neighbours and community.

Due to the stigma of leprosy many communities and children find themselves ostracised, and children are bullied by their classmates and isolate themselves. They want to play with their friends but are pushed away (Uniting to Combat NTDS, 2018). A study from Nepal reported that younger people who develop leprosy may find that it restricts their education (Stigter et al, 2000). The current study also found that a female college student with claw hand deformity due to leprosy was afraid of separation from her friends.

This study observed that half of the women did not have any problem due to the disease; also, their family members, friends and neighbours were more supportive. However, a few women imposed restrictions on themselves and avoided participation in social activities, even though they had a positive environment after disclosure of disease. Lusli et al (2016) reported that the family or community members who know that someone around them is affected by leprosy might want to care for, show kindness and support the person, but more often people are worried about infection and tend to distance themselves.

Women are treated worse if they have leprosy than men and are already dependent on others for their living (Try, 2006). Male dominance in society and the household, in decision making, and income generation is a socio-cultural factor that gives men more respect than women even if they become stigmatised due to leprosy (Try, 2006).A study from Nepal (van't Noordende et al, 2016) found that women affected with leprosy reported sexual and alcohol-related emotional and physical abuse by their husbands. Women affected by leprosy are sometimes abandoned by their husbands. This study also found that a 41- year-old woman, who underwent treatment 10 years ago, was verbally abused by her husband and did not get any support during her treatment (MDT) period.

Depression and anxiety are some of the serious issues among leprosy-affected persons (Scott, 2000; Tsutsumi et al, 2004; Lepra, 2018; Ramasamy et al, 2018). Society's negative attitude towards women is magnified when there are visible signs of leprosy (van'tNoordende et al, 2016). Rafferty et al (2005) observed that many clients are affected mentally, not because of the disease but because of society's rejection of them. This study also observed that a few of the women interviewed were depressed due to the disease and did not disclose this to anyone as they felt ashamed. A 33-year-old woman often had suicidal thoughts because she had leprosy.

A person affected by leprosy, who is frequently ashamed of his/her appearance, is prone to self- exclusion. This can be explained by two factors: the association of the disease with certain behaviours condemned by society, and people's morals and beliefs. The people who are affected can face discrimination, but they can also self-exclude themselves due to the fear of being the subject of stigmatisation once they reveal their condition (Castro, 2016). In this study also, some women were afraid of the community, that people would criticise and isolate them, and even their family members would be separated from their village. In considering marriage prospects, a 53-year-old woman reported that she would prefer her son to get a bride from a family with a history of leprosy, for fear of stigma and discrimination by other families.

Proper footwear along with regular self-care can prevent the development of foot ulcers and ulcer-related complications (Berendt and Lipsky, 2004).Unfortunately, due to fear, self-stigma, experiences of societal stigma and stigmatisation from family members, some women were not able to properly manage self-care and wear protective footwear for their anaesthetic foot in order to prevent deformity. A study from India (Lal et al, 2015) reported that the use of microcellular rubber (MCR) footwear declined during social occasions due to stigma. This study also found that a few of the women were not using the protective footwear (MCR) due to stigma.

People affected by leprosy feared telling their own family about the disease, due to fear of stigma, isolation and social exclusion (Garbin et al, 2015). Moreover, the major cause for the late diagnosis of leprosy in women is the fear of stigma and being ostracized by their family and community (Lepra, 2018). Studies from Nepal reported that husbands left their wives affected by leprosy and also sent their wives away to their parents' house (van 'tNoordende et al, 2016). This study also observed that some women felt afraid to disclose their health status even to their family members, while some limited disclosure to their parents and some to their husbands, since they thought that the disease would create serious problems like isolation, divorce, and discrimination.

It is well known that leprosy is an ancient disease surrounded by lots of myths and misconceptions (The Leprosy Mission Trust India, 2018).The beliefs and perceptions about leprosy were found to be the prominent cause of stigma (Try, 2006). In India, in addition to the fear of infection, false beliefs about leprosy, ignorance about the disease and lower socio-economic status were associated with stigma in leprosy (Nagaraja et al, 2011). Also, leprosy has been considered to be an infliction of wrong-doings and sins (Sinha et al, 2010).This study also observed that women still retain the old beliefs and myths about leprosy.

Women can be triply disadvantaged with regard to health concerns, due to their gender, potential disabilities and the societal stigma which arises from them (Griffey, 2015). If a mother has leprosy, the health and well-being of the whole family can be affected. Fear of passing on the disease can prevent emotional closeness and bonding with her children and also reduce positive health behaviour (Rafferty, 2005). Discriminative attitudes are more common in joint families than nuclear families (Kaur and Ramesh, 1994). Although many people get support from their families, the disease has definite psychological effects (Kaur and Ramesh, 1994).The attitude of the husband and family members even after cure, influences the psychological milieu of the client from immediately getting the diagnosis of the disease (Kaur and Ramesh, 1994).

The potential for stigma and discrimination against persons affected by leprosy continues to challenge early detection and successful completion of treatment. Many people affected with leprosy continue to experience social exclusion, depression, and loss of income and often it is extended to their families also (WHO, 2018).Over the years, with the introduction of MDT and IEC campaigns in India, the stigma and discrimination against persons affected with leprosy is gradually reducing. The National Leprosy Eradication Programme (NLEP)

India has continuously made innovative interventions to eliminate the stigma and discrimination faced by the people affected by leprosy (NLEP India, 2018) in order to fully integrate these people in society.

CONCLUSION

This study concludes that women affected by leprosy still fear the disclosure of the disease. They do not want to disclose their health status to their family and neighbours in order to avoid negative consequences such as the stigma and discrimination attached to the disease. This study shows that the negative behaviour of the community towards women affected by leprosy persists, which subsequently means that women frequently try to conceal their disease from fear of these negative attitudes and practices Even when there was no problem in the community, many women interviewed choose to limit themselves in exposing freely their health condition. In addition, women were apprehensive about their marriages and jobs, and commonly reported psychosocial issues like depression.

Continued education about the disease and its transmission is very essential to spread awareness among the people affected by leprosy, their families, and in the community. It should be a continuous process in order to reduce or remove the stigma and discrimination faced by women in particular. Periodical counselling for women affected with leprosy and their family members would help to improve the psychosocial well-being of these women.

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User Satisfaction with Conventional Lower-Limb Orthotic Devices: a Cross-Sectional Survey in Pakistan

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ABSTRACT

Purpose: *Persons with disabilities affecting lower-limb function use ankle-foot-orthoses (AFO) and knee-ankle-foot-orthoses (KAFO) on a regular basis. However, the effectiveness of these devices in daily use is seldom evaluated, especially in the developing world. This study aimed to evaluate user satisfaction with lower-limb orthotic devices while performing a broad spectrum of daily life activities in Pakistan, and to document the desired outcomes.*

Method: *A survey was conducted among orthotic device users in the out-patient departments of three hospitals in Lahore, Pakistan. The survey questionnaire was devised by adapting the Prosthetic Evaluation Questionnaire to suit orthotics evaluation. Fifty-four AFO and KAFO users participated in the study.*

Results: *Most users felt comfortable while walking on even surfaces with their orthoses. However, donning/doffing these, climbing stairs and performing certain routine activities were considered problematic for most people. Energy conservation was the most desired AFO feature, while the KAFO users wanted automatic knee-joint function.*

Conclusion and Implications: *Overall satisfaction with the existing lower-limb orthoses is adequate. Yet, significant improvements are needed in terms of energy efficiency and comfort while walking on different terrains. Further research is required in order to improve the functioning of the existing orthotic devices.*

Key words: *lower-limb orthoses, polio, stroke, AFO, KAFO*

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INTRODUCTION

Around 1 billion people in the world live with disabilities and 80% of these persons live in developing countries in Asia and Africa (World Health Organisation, 2011). This results in lower educational achievements, fewer economic opportunities and higher rates of poverty among people with disability. Pakistan is the sixth most populous country in the world, with around 2.5% of the total population having a disability (Pakistan Bureau of Statistics, 1998). Among these, the largest group (19%) consists of people marked as "crippled" (unable to walk) in the Census. Today, the country has an estimated 5 million people with disabilities, with as many as 1 million unable to walk independently.

A large number of people suffer from neuromuscular diseases such as polio. It is yet to be eradicated completely in Pakistan (World Health Organisation, 2018). Other causes of disability include muscular dystrophy, spinal cord injuries and stroke. All these conditions lead to muscle weakness or paralysis of the legs. People with polio, in particular, have significantly reduced quadriceps muscle strength (Perry, 1992), making the knee joint unstable during walking. In order to improve stability while standing and walking, these persons are commonly prescribed with ankle-foot-orthoses (AFO) or knee-ankle-foot- orthoses (KAFO) (Lusardi et al,2013). These are custom-built wearable orthoses, usually made from thermoplastics. The effectiveness of these devices in restoring user independence is evident from decades of clinical experience and has also been reported in some clinical trials (Pavlik, 2008). The use of such devices is common in many countries including Pakistan.

In Pakistan, orthotic devices are generally provided by the secondary/tertiary level public hospitals and by various charity organisations. Persons with disabilities visit the out-patient department where a physician recommends a consultation with the orthotics department, usually located within the hospital premises. An orthotist chooses a suitable device after examining the client and taking measurements. The cuffs of ankle-foot-orthoses (AFO) and knee-ankle-foot-orthoses (KAFO) are manufactured with thermoplastics, while uprights are made of stainless steel. Once it is ready, the client is invited to train with the device and the necessary adjustments, if any, are made. The client is then advised to make a follow-up visit after one month.

According to some international studies, as many as 54% of AFO users abandon their devices after a while, citing various reasons such as discomfort, pain, and weight (Gitlin et al,1996; Safaz et al,2015). These issues are generally not obvious in the laboratory and become evident only after prolonged use in daily life. Moreover, many clinical outcome measurement instruments (e.g., Barthel Index, Functional Independence Measure, etc.) do not identify aspects that are important from the user's perspective.

To this end, user survey is an effective tool. A few studies have used qualitative and quantitative surveys to evaluate the users' satisfaction with the orthoses. Fisher and McLellan (1989) conducted a survey in England, using a questionnaire to assess clients' satisfaction with lower-limb orthoses. The survey questionnaire focused largely on the comfort and fit of the device, along with provision delays and general satisfaction. Overall, 16% of the AFO users revealed dissatisfaction with the weight of their device and its failure to improve mobility. However, information associated with pain, energy expenditure, and ability to perform activities of daily life was not covered by the questionnaire. Similarly, Phillips et al (2011) did a qualitative study with 15 AFO users living with Charcot-Marie-Tooth (CMT) disease in the UK. The study ranked the top advantages and drawbacks of the AFOs, based on user opinion. More recently, O'Connors et al (2016) interviewed 15 AFO and KAFO users from the NHS service in England. They assessed the clinical effectiveness of orthotic management for an unstable knee following neuromuscular and central nervous system (CNS) diseases. The study also went a step further and inquired about the prime desired outcomes and valued features in their devices. Similarly, surveys assessing user satisfaction have been carried out in countries such as Italy (Vinci and Gargiulo,2008), with insights into the factors affecting the compliance of orthotic devices with the users.

However, these studies were all limited in scope, either in terms of the type of device (mostly involving only AFO users) or in evaluating only a few aspects of daily life (e.g., the fitting or pain/fatigue or falls). Moreover, these were conducted in advanced countries and usually carried out a qualitative assessment. To the author's knowledge, no such studies have been carried out in the developing world to quantify the satisfaction and expectations of both AFO and KAFO users.

Objective

To address this gap, a pilot survey of AFO and KAFO users was conducted in three different hospitals in Pakistan. The purpose of the survey was two-fold:

- To evaluate user satisfaction with lower-limb orthotic devices while performing a broad spectrum of daily life activities in Pakistan, and
- To identify users' desired outcomes and features related to the orthotic devices.

METHOD

Study Setting

From June to August 2018, surveys were conducted among clients in the outpatient departments of three hospitals (Pakistan Society for the Rehabilitation of the Disabled (PSRD) Hospital, Ghurki Trust Teaching Hospital, and Shahbaz Sharif Indus Hospital) in Lahore, Pakistan. A single interviewer interacted with the clients in person, and asked them questions from a questionnaire in the local language (Urdu). Interviews were conducted in the presence of a healthcare professional.

Study Sample

Using convenience sampling, study participants were directly recruited from the out-patient departments. Participants were screened on the basis of age, types of device used and the experience level.

Inclusion criteria:

- Persons at least 15 years of age,
- Only AFO and KAFO users, and
- Those who had used the orthotic device for 1 year at the minimum.

The survey participants comprised 41 male and 13 female users, from 15 - 60 years of age. All the users currently employed a custom-moulded orthosis made of thermoplastics, as prescribed by the doctor of physiotherapy and fabricated in the in-house facility.

Survey Questionnaire

Although a validated Prosthetic Evaluation Questionnaire (Legro et al,1998) has been developed and used extensively to evaluate functional outcomes of lower-limb prostheses (Boone and Coleman, 2006), no questionnaire exists for evaluating orthoses. Proebsting et al (2017) recently adapted the PEQ to compare the effectiveness of the C-brace (a microprocessor-based KAFO device) with a traditional KAFO device. Using a similar approach, the current author adapted the Prosthetic Evaluation Questionnaire. While reducing its size from 9 domains to the 4 most relevant domains, a few questions were added relating to the local community (e.g., the use of an Indian toilet seat) and users' desired outcomes from their orthotic devices. The survey was reviewed by all the collaborators who were physiatrists and engineers. The questions were analysed for their relevance to the objectives of this study and their proper construction.

The survey comprised 46 questions in total. After the basic biodata questions, there were a few questions pertaining to the disability (the type, duration, etc.) and the rest were related to users' perceptions of their existing devices, categorised into four domains: general satisfaction, bodily discomforts, ability to move around, and daily activities. The selected domains reflected the focus of this study on the functional aspects of these devices. For most questions, users rated their satisfaction with different aspects and their ability to perform certain activities with their existing orthoses on a symmetric Likert-type Scale of 1-5. A higher rating indicated a more favourable condition (more happiness, ease of performing an activity, etc.), except for the frequency-related questions (pain, falls, etc.). A few questions required a simple binary response, such as, for the weight of the device 'bearable vs. unbearable'. (The survey questionnaire has been included as an Appendix.)

An important objective of this study was to identify users' preferences in terms of their device features. To achieve this, in the last section, the users were asked to suggest 3 improvements they would like to have in their devices. They could either choose from a list of 12 features related to the form and function of the device or could suggest any feature of their own. The choices were presented to the participant in no specific order and were explained by the interviewer wherever necessary.

Data Analysis

The collected data was entered into the SPSS® (IBM SPSS Statistics, version 25) for further analysis. Descriptive statistical analysis was performed on the data from all categories, collectively as well as separately, for both user groups (AFO and KAFO users). The responses to the final question regarding the desired features were grouped together and ranked accordingly.

Ethics Approval

Ethics approval was granted by the departmental Ethics Review Committee at the University of Central Punjab in Lahore, Pakistan. Many of the participants could not read or write, so their verbal consent was taken on the spot to ensure a uniform protocol throughout the survey.

RESULTS

Out of a total of 54 participants, 37 individuals (26 males, 11 females) used a KAFO device with a locked knee version, while 17 individuals (15 males, 2 female) used an AFO device. A large majority of participants lived with either polio (38) or stroke (14). Two users had orthoses following a traumatic injury (1 AFO and 1 KAFO user). Of the 38 people living with polio, 33 had weakness in one leg only. All people with polio (except for 2) used KAFO, while all the 14 people with stroke used an AFO.

The mean age of the participants was 33.5 ± 9.9 years. Two-thirds of the participants belonged to the 26 – 45 years age bracket. Though the average age of the participants was similar for both user groups, there was a large difference between the mean numbers of device-use years (4.4 years for AFO users vs. 13 years for KAFO users). The users' level of experience with their device varied greatly, ranging from a minimum of 1 year to a maximum of 37 years.

Table 1: Profile of the Orthotic Device Users in the Study

Attribute	AFO users	KAFO users
Age (years) Mean ± s.d.	34.8 ± 10.3	32.9 ± 9.8
No. of years since using the device, Mean ± s.d.	4.4 ± 7.0	13.1 ± 11.0
Reason of disability:	Stroke: 14 Polio, one affected leg: 02 Trauma: 01 Total: 17	Polio-one affected leg: 31 Polio-both legs affected: 05 Trauma: 01 Total: 37

While 89% of all study participants used their device for 6 hours or more during the day, 65.4% wore it for more than 8 hours. All the users employed the device regularly while walking.

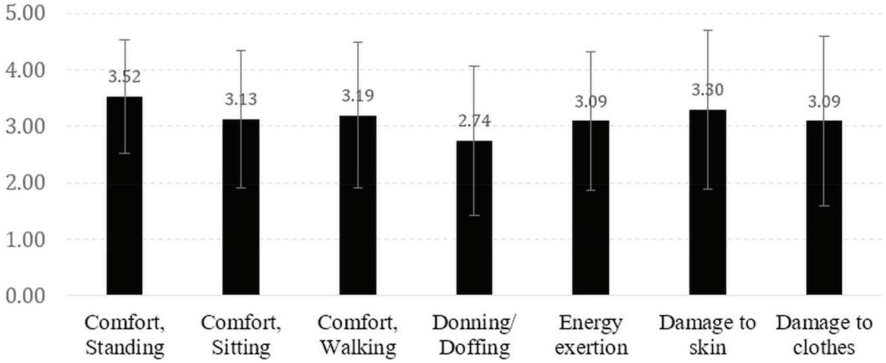
Perceived Comfort and Overall Satisfaction

Questions regarding perceived comfort and wearability of the device resulted in mixed responses. Figure 1 shows the mean ratings for some of these criteria. As a whole, the comfort in standing, sitting and walking had a mean rating of over 3 out of 5. The donning/ doffing of the device received the least mean rating (2.74±1.32) in this category. Moreover, the energy exertion received a mean rating of 3.1 (±1.2), corresponding to a 'moderate' level of exertion.

The question regarding overall satisfaction with the existing device received a mean rating of 4.07 (±0.866). The majority of the users (38 or 70%) gave a rating of 4 or above for this criterion (corresponding to the word choices of 'happy' and 'extremely happy').

A majority of users (51 out of 54) rated the weight of their device as 'bearable'. Questions regarding damage to the skin and clothes by the device received a mean rating of 3.3 and 3.1 respectively, with large standard deviation among subject responses.

Figure 1: Results regarding Comfort and Satisfaction with the Orthoses



Bodily Discomfort and Falling

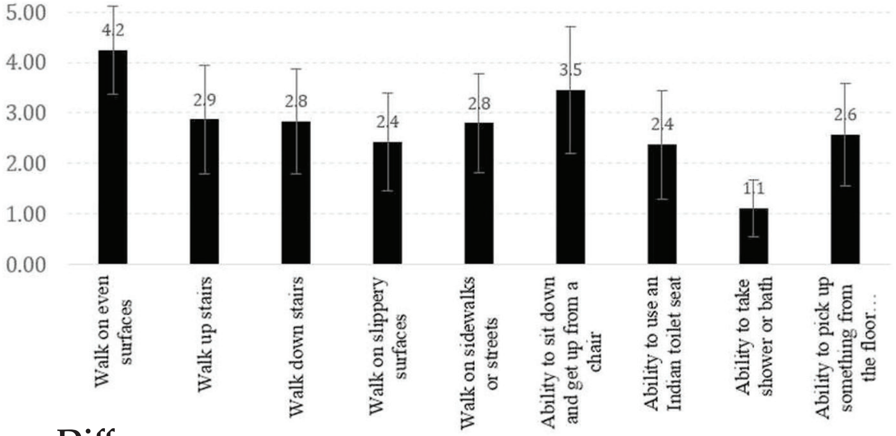
The survey included five questions regarding sweating and leg and back pains. Forty-one users (76%) reported 'moderate' to 'extreme' sweating inside their orthoses during summer. The mean rating was 2.81 (±1.06).

Between 30-70% of the users reported the occurrence of leg and back pain (once per week or more) while using their devices. However, the intensity of pain ranged from 'mild' to 'moderate' in most cases. Among the participants, 31 users (14 AFO and 17 KAFO) experienced at least one fall while wearing their device, while 23 reported very frequent falls (once a week or more).

Locomotion and Other Daily Activities

There was a clear distinction between walking on even and rough surfaces, and stair ascent/descent. While walking on flat ground was deemed to be easy for most individuals (mean rating of 4.24 ± 0.867), walking outdoors and climbing/descending stairs were difficult for most of them, reflected by their mean ratings between 2.4 and 2.9 for these activities (Figure 2). Most users reported difficulty in performing other tasks, such as using a toilet or taking a bath, with very low mean ratings.

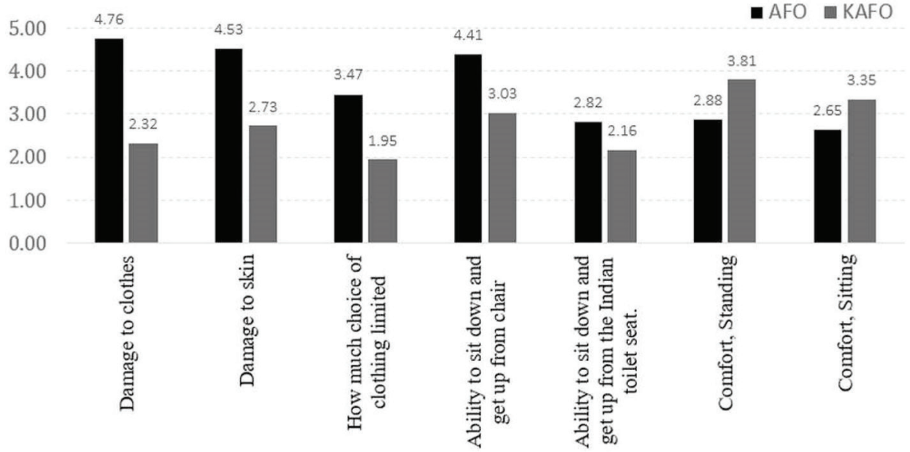
Figure 2: Results regarding Walking and Other Activities of Daily Life



Inter-group Differences

The combined responses from both the ankle-foot-orthoses users and the knee-ankle-foot-orthoses users (presented in Figure 2) gives a holistic picture of the satisfaction levels of users in Pakistan. However, the two user groups reported different pain points in some aspects of their devices. Figure 3 shows separate mean ratings for questions where the maximum variation between the two groups was observed. The largest difference in mean ratings was observed for the questions related to damage to skin and clothes. The KAFO users reported much lower rating to their orthoses in terms of damage to skin and clothes and their choice in clothing. Similarly, the ability to sit down and get up from a chair and the Indian toilet seat was also reportedly much more difficult for the KAFO users. However, in terms of standing and sitting with the orthoses, KAFO users rated their comfort higher than the AFO users.

Figure 3: Mean Ratings given by AFO (black) and KAFO (grey) Users for Key Areas of Difference between the AFO and KAFO Groups

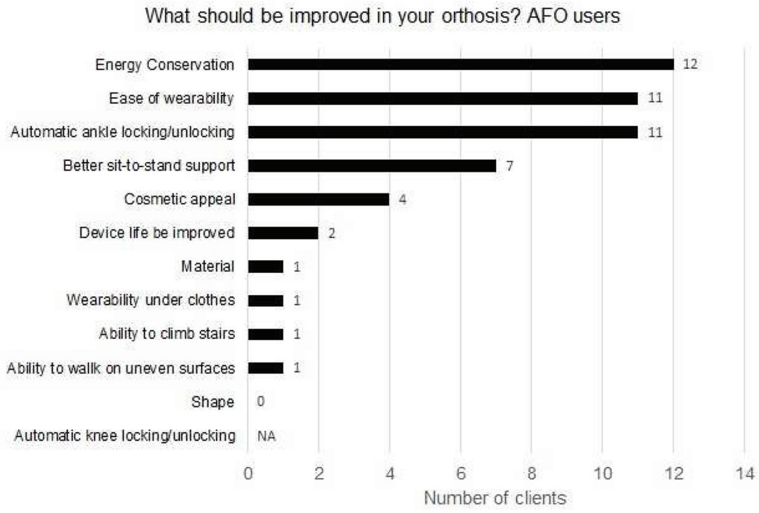


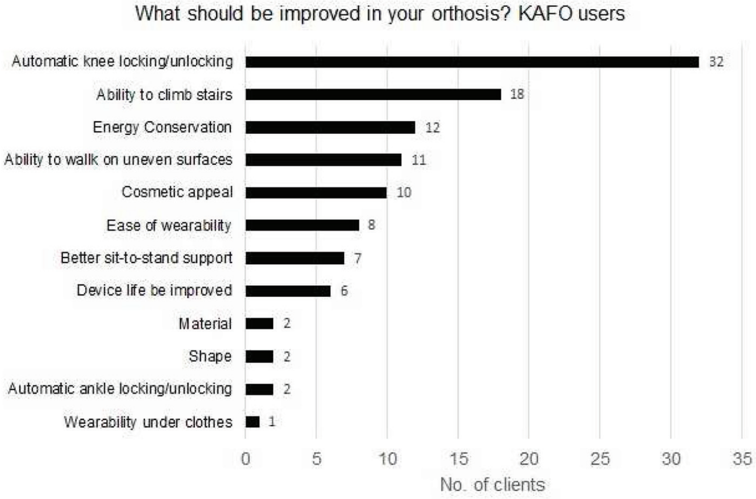
Difference was also observed in terms of falls and trips. Among the AFO users, 14 out of 17 (82%) reported a fall or trip while walking with their orthoses, as compared to 46% of KAFO users.

Future Improvements

The results from the last question regarding the users' desired outcomes are summarised in Figure 4 for AFO and KAFO users separately.

Figure 4: Desired Improvements based on Opinions of (a) AFO users and (b) KAFO users





'Energy conservation' was considered the most desired aspect by the AFO users, with 12 out of 17 participants selecting it among their top three choices. This was followed by 'ease of wearability' and 'automatic ankle joint function' options. For the KAFO users, the most desired feature was 'automatic knee locking/ unlocking', with 32 out of 37 participants picking this option. It was followed by the 'ability to climb stairs' and 'energy conservation' aspects.

DISCUSSION

The main purpose of this study was to evaluate the performance of low-cost orthotic devices from the perspective of users in Pakistan. The majority of users expressed overall happiness while using their existing device. However, wearability of the device (putting on and taking off) was considered a difficult aspect. Other areas of dissatisfaction included walking on uneven surfaces, toileting, sweating and skin damage.

Comparison of mean scores between ankle-foot-orthoses users and knee-ankle-foot-orthoses users revealed a few differences in areas of concern. The issue of skin and clothes damage, which is a key concern for KAFO users, could be attributed to the design of the device and would require resolution at that level. However, some other aspects are a result of the users' underlying disease condition and should be taken into consideration in order to fully understand their dynamics. For example, it is possible that stroke-related gait deficits (Weerdesteijn et al,2008) were responsible for more frequent falls among AFO users. Nevertheless, these results give an insight into the key areas that orthoses designers need to focus on.

A major contribution of this article is the identification of desired outcomes from the users' perspectives. A large majority of the KAFO users wanted to automate their knee joint function in order to free-up their knee joint when needed (e.g., during the swing phase of walking). It is well known that locking the knee joint during walking results in abnormal gait pattern involving compensatory movements (hip hike, leg circumduction) and high energy expenditure (Waters and Mulroy,1999; Zissimopoulos et al,2007). Rehabilitation specialists have long recognised the need to remove this constraint (Michael and Bowker,1994). Moreover, as this survey result demonstrated, this constraint also prevented the users from effectively performing certain activities such as kneeling on the floor or using the Indian toilet. In order to address this issue, the Stance Control KAFO (SC-KAFO) has been developed which unlocks the knee joint during swing, using a mechanical switching mechanism (Irby et al,2005; Yakimovich et al,2009) or by an onboard computing unit (e.g., the C-Brace by Ottobock). While these innovations have demonstrated improved gait function and reduced energy expenditure, several design and cost challenges need to be addressed before these devices may be used on a mass scale (Bernhardt et al,2006; Yakimovich et al,2009). Local research into the design of Stance Control knee joints which can be retrofitted into the existing KAFO versions would be of value in this context.

On the other hand, AFO users predominantly selected energy conservation as the top desired outcome from their device. It can be speculated that while existing AFO devices improve the walking efficiency of stroke clients, users expect even better energy efficiency. Keeping in view these results and existing literature that reported an increased energy cost per meter for stroke survivors (Zamparo et al,1995; Waters and Mulroy,1999), research towards reducing this cost by using elastic elements (Collins et al,2015) in the orthoses may be of interest in this regard.

The results of the current study highlighted some challenges specific to the local society. Due to the hot climate, both user groups reported considerable sweating inside their orthoses. Similarly, they reported difficulty in using the squat-type Indian toilet which requires extensive knee-bending. To the best of the author's knowledge, these aspects have not been highlighted in earlier survey studies.

Limitations

This study has several limitations. First of all, only orthoses users were recruited at follow-up appointments in hospitals. Hence, there was no possibility of interaction with the dissatisfied users who had stopped using their devices. This may have positively skewed the overall satisfaction rating for the study sample. Moreover, the surveys took place in Lahore, a predominantly urban area in the plains. Future studies are needed, with a larger and more diverse sample, for confidence in generalising these results to samples that are demographically and geographically different.

The survey questionnaire for this study was derived from the Prosthetic Evaluation Questionnaire, and its validity in the case of orthoses users is not known. However, complete validation of a questionnaire requires rigorous development and statistical testing (Boone,2006) which was not the purpose of this study. There is a need for a validated questionnaire to make the results of future studies comparable and more reliable.

CONCLUSION

The conventional ankle-foot-orthoses and knee-ankle-foot-orthoses for people living with polio and stroke in Pakistan need improvement in terms of energy efficiency and walking on uneven terrain. In contrast to the previous studies indicating less weight and cosmetic appeal as prime desired outcomes for AFO user groups, the users in this study seemed more concerned about the functionality of their devices. Only about one-fourth of the surveyed users chose cosmetic appeal as their preference (see Figure 4).

These results will help researchers in user-centric decision-making in the design of these devices and can guide future research activities. The results are also useful for designing rehabilitation services for persons with disabilities.

ACKNOWLEDGEMENT

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Appendix

Serial Number: US________

Date ____________________

Location ________________

A survey on the effectiveness of conventional lower-body orthoses

BioMechatronics Lab,
University of Central Punjab, Lahore

QUESTIONNAIRE

Patient information:

Name: ____________________

Gender: ☐ Male ☐ Female

Age: __________years

City of residence: ____________

Occupation: ______________

Income: __________________

Disability information:

(i) Reason of disability:

☐ Multiple Sclerosis ☐ Muscular Dystrophy

☐ Stroke ☐ Spinal Cord Injury

☐ Polio (☐ One Leg (☐ Left ☐ Right) ☐ Two Leg)

☐ Other______________

(ii) Time since disability: ________ years

(iii) Using any assistive device: ☐ Yes ☐ No

(iv) Type of device used: ☐ AFO ☐ KAFO

(v) Using since: _____years

(vi) Name of brand/manufacturer: ______________

(vii) Cost paid:__________________

Section 1: General

Q1: For how many hours do you use the device?	0-2 ☐ 1	2-4 ☐ 2	4-6 ☐ 3	6-8 ☐ 4	8+ ☐ 5
Q2: How often do you use this device during walking?	Rarely ☐ 1	Occasionally ☐ 2	Often ☐ 3	Usually ☐ 4	Always ☐ 5
Q3: How do you categorize the weight of your device?	Unbearable ☐ 1	Bearable ☐ 2			
Q4: How would you rate your comfort while standing using your orthosis?	Not at all Comfortable ☐ 1	Somewhat uncomfortable ☐ 2	Neutral ☐ 3	Somewhat Comfortable ☐ 4	Very Comfortable ☐ 5
Q5: How would you rate your comfort while sitting using your orthosis?	Not at all Comfortable ☐ 1	Somewhat uncomfortable ☐ 2	Neutral ☐ 3	Somewhat Comfortable ☐ 4	Very Comfortable ☐ 5

Q6: How would you rate your comfort while walking using your orthosis?	Not at all Comfortable ☐ 1	Somewhat uncomfortable ☐ 2	Neutral ☐ 3	Somewhat Comfortable ☐ 4	Very Comfortable ☐ 5
Q7: How would you rate the ease/ difficulty of donning and doffing of your orthosis?	Extremely difficult ☐ 1	Difficult ☐ 2	Neither Easy nor Difficult ☐ 3	Easy ☐ 4	Very Easy ☐ 5
Q8: How would you rate the energy exertion during walking with your orthosis?	Extreme ☐ 1	Significant ☐ 2	Moderate ☐ 3	Small ☐ 4	Negligible ☐ 5
Q9: How would you classify the damage done by the orthosis to your <u>skin</u>?	Extreme ☐ 1	Significant ☐ 2	Moderate ☐ 3	Small ☐ 4	Negligible ☐ 5
Q10: How would you classify the damage done by the orthosis to your <u>clothes</u>?	Extreme ☐ 1	Significant ☐ 2	Moderate ☐ 3	Small ☐ 4	Negligible ☐ 5
Q11: Overall, how happy are you with your device?	Extremely Unhappy ☐ 1	Unhappy ☐ 2	Neutral ☐ 3	Happy ☐ 4	Extremely Happy ☐ 5

Section 2: Bodily Discomforts

Q1: How much do you sweat inside orthosis in summer?	Extreme ☐ 1	Very ☐ 2	Moderate ☐ 3	Slight ☐ 4	Not at all ☐ 5
Q2: How often have you experienced back pain?	☐ Never	☐ 1-2 Times per Week	☐ 3-6 Times per Week	☐ Several times everyday	☐ Almost all the time
Q3: If yes, what is the intensity of the pain?	Extremely Intensive ☐ 1	Intensive ☐ 2	Moderate ☐ 3	Mild ☐ 4	Negligible ☐ 5

Q4: How often have you experienced pain in the leg?	☐ Never	☐ 1-2 Times per Week	☐ 3-6 Times per Week	☐ Several times everyday	☐ Almost all the time
Q5: If yes, what is the intensity of the pain?	Extremely Intensive ☐ 1	Intensive ☐ 2	Moderate ☐ 3	Mild ☐ 4	Negligible ☐ 5

Section 3: Ability to move around

On a scale of 1-5, how would you rate your ability…

	Extremely difficult	Difficult	Neither Easy nor Difficult	Easy	Very Easy
Q1: To walk on even surfaces?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
Q2: To walk upstairs?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
Q3: To walk downstairs?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
Q4: To walk on slippery surfaces?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
Q5: To walk on sidewalks or streets?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
Q6: To stand for a long time?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

Q7: Have you tripped or slipped during walking while wearing orthosis?	☐ Yes	☐ No			
Q8: If yes, how often have you experienced fall down?	☐ Once a Month	☐ Once a Week	☐ 2-3 Times per Week	☐ 4-6 Times per Week	☐ Several Times Everyday

Section 4: Daily Activities

On a scale of 1-5, How would you rate your ability…

	Ex tremely difficult	Difficult	Neither Easy nor Difficult	Easy	Very Easy
Q1: To sit down and get up from a chair?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
Q2: To sit down and get up from the Indian toilet seat?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
Q3: To take shower or bath safely?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
Q4: To kneel down to pick up something off the floor?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

Q5: How limited is your choice of clothing due to your orthoses?	Extremely Limited ☐ 1	Limited ☐ 2	Somewhat Limited ☐ 3	Slightly Limited ☐ 4	Not at all ☐ 5
Q6: Do you drive any conveyance?	☐ Yes	☐ No			
Q7: If yes, which one you are using for travelling?	☐ Bicycle	☐ Motorbike	☐ Rickshaw	☐ Car	☐ Other
Q8: Rate your ability to drive this vehicle?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

Section 5: Future Design

In your opinion, what should be IMPROVED in conventional knee braces/ orthoses? (tick 3 most applicable)	☐ Ability to walk on uneven surfaces
	☐ Ease of wear ability
	☐ Better sit-to-stand support
	☐ Automatic knee locking / unlocking
	☐ Automatic ankle locking / unlocking
	☐ Energy conservation
	☐ Ability to climb stairs
	☐ Device life be improved
	☐ Cosmetic appeal
	☐ Wearability under clothes
	☐ Shape, please elaborate _______________
	☐ Material, please elaborate _____________
	☐ Other, please specify __________________

Additional comments/suggestions:

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Thank you for your time

Mixed-Methods Programme Evaluation of Disability Equality Training (DET) in Mongolia

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ABSTRACT

Purpose: *An evaluation of a disability equality training (DET) programme, based on the social model of disability, was conducted to explore the changes in the participants' attitudes and behaviours in Ulaanbaatar, Mongolia.*

Methods: *This study is composed of two parts. First, the participants' attitude changes during DET sessions were examined through a descriptive quantitative and qualitative analysis of questionnaires and related documents. Second, the behavioural changes at the organisational and individual levels, the impact on society, and related factors were explored by quantitative and qualitative analysis of good practice cases: 39 participants were selected through purposive sampling and semi-structured interviews were conducted.*

Results: *It was found that most participants adopted the social model perspective within these sessions. A qualitative content analysis of the good practice cases also found that the majority of participants attempted to change their social environments after the sessions. Thematic analysis identified promotional factors, such as within-organisation dynamics and compatibility and barriers at the individual and organisational levels, which were associated with participants' behaviours after DET sessions.*

Conclusion: *The implications of these findings are discussed in connection with the strategic implementation of DET to promote disability-inclusive development. Future studies should examine the effectiveness of a strategy by considering the factors identified in this study and by using a reliable sample in various settings where DET sessions are conducted.*

Key words: *social model of disability, disability issues, agent of change, mixed methods, international development*

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INTRODUCTION

Disability Equality Training (DET) has been implemented worldwide, from developing countries to developed countries. DET originated in the United Kingdom in the 1970s to promote the implementation of the Disability Discrimination Act (Gillespie-Sells & Campbell, 1991; Kuno, 2009; Mishima, 2009). As of 2019, DET has been implemented in more than 30 countries (Disability Equality Training Forum, n.d.). The sessions are currently conducted by various organisations, some with support from international bodies (Lordan, 2000; Kuno, 2009). Furthermore, international donor organisations, such as the Japan International Cooperation Agency (JICA), include DET in programmes related to disability and development in the Global South. However, a research gap exists regarding the evaluation of the DET programme and the factors that are associated with participants' behavioural changes after the sessions.

DET, which is based on the social model of disability, is implemented by DET facilitators who are disabled persons in order to create an inclusive society (Gillespie-Sells & Campbell, 1991). DET is often compared with Disability Awareness Training (DAT). Participants in DAT are likely to have simulated experiences of activity limitations, whilst those in DET are likely to experience social barriers and consider actions to address the issues (French, 1992; Carr et al, 2012). Participants in DET sessions, which include active dialogue between those present, are expected to shift their perspective to embrace the social model of disability and become agents of change in society (Carr et al, 2012).

Although literature suggests the importance of evaluating a DET's impact on society, there are a limited number of papers and not enough evidence (Walker, 2004; Igei, 2019). Few researchers have attempted an evaluation of the impact of DET on individual behaviours and organisational actions. Lordan (2002), for instance, mentions a case of physical accessibility that was improved after DET sessions, but the relationship between DET and the improvement is unclear in the study. As an exception, Igei's study (2020) applies randomised controlled trials to the impact evaluation of DET on taxi drivers in South Africa. The study reveals statistically significant differences in taxi drivers' attitudes and behaviours between an intervention group and control groups, such as offering appropriate assistance for passengers who are disabled persons. Since only a limited number of articles with limited target groups exist, the comprehensive evaluation of DET programmes should be performed.

In addition, most academic papers examining DET appear to give insufficient consideration to context and factors of participants' changes in society. Some researchers, for instance, argue that DET sessions should be flexible in accordance with participants' needs and background, and that they would be more effective if other interventions are mixed strategically with the sessions (Millington & Mottram, 1999; Reeve, 2000; Parkinson, 2006; Kuno, 2009). Whilst it would depend on the objectives and methodology of studies whether the main factors should be controlled, it is clear that describing the basic information of DET and its set interventions is necessary.

Few studies examine the factors and experiences leading to actual actions of DET participants, both as individuals and as agents within organisations (Higashida, 2020; Igei, 2020). Research indicates it is likely to be more difficult to capture the transition process of participants' shifting behaviours than their attitudes (Walker, 2004). Since an individual's behaviour after participating in DET appears to depend on the person's own choices in a unique social environment, it is important to consider multiple aspects, such as personal background and organisational factors as well as the influence of DET sessions.

Aim

This study aims to examine the DET participants' changes of attitudes and behaviours, whilst exploring the factors associated with their actions after DET sessions.

METHOD

Study Setting

Mongolia is one of the developing countries where DET has been strategically implemented. The study site was Ulaanbaatar, the capital city, where about half of the national population, 1.49 million people, is concentrated (National Statistics Office of Mongolia, 2020). A technical cooperation project for promoting social participation of persons with disabilities in Ulaanbaatar city (DPUB) was jointly conducted from May 2016 to May 2020, by the Ministry of Labour and Social Protection (MLSP) in Mongolia and the JICA. The DPUB involved outcomes and activities focused on training DET facilitators who are all disabled persons (JICA, 2020). In addition, the Mongolian government listed DET as a disability-inclusive awareness activity within Goal 7 of the 'National Programme for Promotion of

Human Rights and Participation of Persons with Disabilities 2018-2020' (MLSP, 2019).

Figure 1 gives an example of a standard session by the DET Forum Mongolia. The basic style is a 3-hour session that the DPUB strongly recommends but it is dependent on the request and situation of participant organisations. For example, a shortened version of one and a half hours (called 'an introduction type') is also used. Besides, after conducting DET, disability-inclusive service and manner training focusing on visual impairment, hearing impairment and mobility impairment is often conducted (called 'a set type').

Figure 1: An example of a DET Announcement (simplified version)

Disability Equality Training

DET Forum Mongolia

Disability equality training (DET) is a disability awareness session used in 38 countries worldwide. It is a participatory learning method using illustrations and videos. Its distinctive feature is that disabled people are in charge of facilitators and encourage participants' learning.

What is a disability? Where is it? What causes it? Through the dialogue between participants and facilitators, participants will discover the 'disabilities' hidden in the consciousness of society and people, and learn the approach of creating action plans and taking actions for addressing the issues.

- Date and time: 14:00-17:00, 19 January 2019
- Contents

14:00–14:15 Self-introduction of facilitators and participants with warm-up

14:15–15:30 DET First half: 'What is a disability?'

- Exercise 1: What is a disability? (First time)
- Exercise 2: Illustration analysis
- Exercise 3: Video analysis
- Exercise 4: What is a disability? (Second time)
- Halfway wrap-up: Focus on the Convention on the Rights of Persons with Disabilities

15:30–15:45 Coffee break

15:45–17:00 DET Second half ‘Taking action’

- Exercise 5: Inclusion and integration
- Exercise 6: Listen to the voices of disabled people
- Exercise 7: Good practice of reasonable accommodation
- Exercise 8: Action plans
- Wrap-up and closure

In total, 46 disabled persons became DET facilitators in Mongolia, including 11 senior facilitators. Of the senior facilitators, three became DET trainers who can train new facilitators, through a specific training course in December 2019. As of February 2020, 312 DET sessions had been held by the DET facilitators, and 10,250 people participated in the sessions (MLSP, 2020). Thus, Ulaanbaatar is an appropriate place for evaluating the impact of DET on factors influencing the changes in participants’ attitudes and behaviours.

Research Design

The project team discussed an appropriate and feasible design for this study, beginning in February 2019. The initial team included the DPUB’s project members, namely, from the MLSP and JICA, and disabled people. The comprehensiveness of the research scope was considered, together with a sense of field reality, and practical methods that local stakeholders can apply in the future.

The evaluation research design was then created based on the four-level approach framework (Kirkpatrick & Kirkpatrick, 2006; Yonehara, 2014; Higashida, 2020), which comprised reaction and satisfaction (1st level), learning and understanding (2nd level), behavioural change (3rd level), and results and impacts (4th level). A mixed-methods approach was applied to the four-level approach from a pragmatic perspective (Creswell & Clark, 2017).

Considering the context of DET in Mongolia, it was decided to include the following components in two phases. In the first phase, the researchers analysed the quantitative and qualitative data from those who had just completed a DET session, including questionnaires focusing on the participants’ satisfaction with DET (1st level), and the degree of change in attitudes or adopting the perspective of the social model of disability (2nd level). In the second phase, data was analysed from semi-structured interviews with those who had completed a DET session, focusing on the degree and factors of change in behaviours (3rd level), and the impact of these sessions as perceived by the participants (4th level).

The Joint Coordination Committee consisting of 30 participants, including 15 government officials and 8 representatives from non-governmental organisations (such as Disabled People's Organisations), officially approved the plan of this evaluation research project on 5th July, 2019.

Phase One

The degree of satisfaction (1st level)

In each DET session, participants were required to anonymously fill out questionnaires that DET facilitators distributed and collected after the session. This was done between 28th October, 2016 and 22nd June, 2018 (n = 2,475). The five-point Likert scale questions included 'To what extent do you think DET is useful to you?' and 'To what extent do you think that the understanding of disability has advanced?' (from 1 = 'not at all' to 5 = 'very much'). Initially, these questionnaires were intended to provide feedback to the DET facilitators to reflect on their own practices. They were also useful for a simple analysis of the degree of the participants' satisfaction with the sessions. Approximately 50% (n = 1,238) of the collected answers were extracted using a systematic extraction method.

The degree of adopting the perspective based on the social model of disability (2nd level)

The following method was used to analyse the degree to which participants changed their attitudes according to the social model of disability. The researchers collected the worksheets that participants were required to fill out twice in each DET session. These had two blank spaces, each with heading words—'Disability is…' ('Хөгжлийн бэрхшээл гэдэг нь'). Participants were instructed to write down their thoughts following the heading, before and after certain DET exercises such as group work of problem analysis on social barriers. This offered information on how individual participants changed their thoughts through DET exercises.

Data was collected in two different situations. Each DET session varies in terms of group dynamics between participants, the style and characteristics of DET facilitators, different materials and physical environments such as venues, among others. Two sessions were held at the same venue but were conducted by different facilitators using different materials. For instance, a video titled 'Talk', which was edited in the UK and translated into Mongolian, was used in the first session. Another video titled 'I am You', which was edited in Japan and also translated, was used in the second session. The number of collected worksheets was 26 (from 7 males and 19 females; the response rate was 86.7%) in the first session (June 2019) and 18 (from 2 males and 16 females; the response rate was 85.7%) in the second session (September 2019).

Qualitative content analysis was applied to the collected document data by two evaluators (the first author and the research assistant). After an open coding based on the meaning of the description, tentative categories were created. When the two evaluators had different opinions on the categorisation, they would both discuss and reach an agreement. Six categories with their sub-categories were generated, namely, 'traditional/religious matter', 'individual impairments/dysfunction', 'different conditions and special needs', 'physical environment and people's attitudes', 'interaction between impairments and environment' and 'discrimination, rights and participation'. In the next step, a simple tabulation was performed to apply an appropriate category to each relevant clause for the quantification and summarisation of the data. Afterwards, each sentence was classified into one major disability model—'individual or traditional/religious', 'social' and 'other'—analysing changes within every individual before and after the exercise. A qualitative data analysis software, MAX QDA2018, was used in the process.

Phase Two

The degree and factors of change in behaviours after a DET session (3rd level) and the perceived impact (4th level)

Phase two examined the degree and factors of behaviour change after a certain period following the DET session, and the impact perceived as well as the actions taken afterwards. This phase focused on the participants' subjective experiences, including perceived processes and factors of actions taken within their own individual and organisational contexts. Mainly qualitative data collection and analysis were applied to semi-structured interviews, supplemented by quantitative analysis on the same data.

The interview candidates were selected by purposive sampling. The selection criteria were those who (a) had participated in a DET session within the last 18 months and (b) were recommended by DET trainers and the project members because they were expected to show a change in attitude and take action. Of the 43 candidates selected by this method, 39 people (15 from the government sector, 14 from public facilities and institutions and 10 from the non-governmental or business sectors) expressed willingness to be interviewed. The interviewees were 11 males and 28 females. Their average age was 34.3 ± 9.9 years. Approximately 82.1% participated in a standard session of 3 hours, including a set session with other interventions.

The semi-structured interviews were conducted individually, followed by field visits if necessary, between September and December 2019. The three interviewers (authors) used interview guides and recorded the proceedings with the written consent of the interviewees. Each interview lasted between 45 and 90 minutes.

By using the data that could be converted to nominal or ordinal scales, actions taken and factors associated with the participants' behavioural changes at the organisational and individual levels after DET sessions were explored. Reported cases were categorised into 'physical accessibility improvement', 'informational accessibility improvement', 'awareness raising', 'livelihood supports', 'service/manner improvement', 'survey and analysis' and 'promotion of social participation'. Multivariate discrimination analysis, namely Hayashi's Quantification method type II, was applied to the data.

Thematic analysis, whilst referring to Braun and Clarke (2006), was applied to the narrative transcription of the 39 interviews. The initial codes were generated based on similar meanings or semantic contents in segments of data. Using the initial codes, the researchers searched for themes within candidates, focussing on the process, factors and contents of participants' reported behaviours and attitudes. After reviewing these candidates, the main themes and sub-themes were defined and named. Main themes consisted of 'Promotional factors at the individual level', 'Promotional factors at the organisational level', and 'Barriers to taking an action'. MAX QDA2018 software was used for the analysis. Each interviewee was given a letter and number combination as an anonymous identification code during the analysis.

RESULTS IN PHASE ONE

The Degree of Satisfaction (1st level)

The first question, 'To what extent do you think DET is useful to you?', had an average of approximately 4.4 ± 0.8 in the five-point Likert Scale. The second question, ‘To what extent do you think that the understanding of disability has advanced?’, had an average of about 4.1 ± 0.9.

The Degree of Acquiring the Perspective based on the Social Model of Disability (2nd level)

Table 1 displays the results of the qualitative content analysis on the description of disability given by participants, before and after DET group work. The percentage of descriptions of ‘traditional/religious matter’ and ‘individual impairments/dysfunction’—which can be considered descriptions based on the traditional medical model of disability—decreased from 53.0% before DET session activities to nought afterwards. By contrast, the percentage of descriptions of ‘physical environment and people’s attitudes’ and ‘interaction between impairments and environment’—which can be considered descriptions based on the social and interactional models of disability—increased from 7.6% and nought, respectively, before DET session activities, to 36.9% and 6.0% afterwards.

Table 1: Participants’ Attitude categories towards Disability before and after DET

Category	Subcategory	Before		After	
		n	%	n	%
Traditional/ religious matter	Religious understanding	2	3.0	0	0.0
	Traditional understanding	1	1.5	0	0.0
	Spiritual power	1	1.5	0	0.0
Individual impairments/ dysfunction	Dysfunction due to impairments	16	24.2	0	0.0
	Individual impairments	12	18.2	0	0.0
	Lack of efforts and confidence	3	4.5	0	0.0
Different conditions and special needs	Special needs and aid	7	10.6	4	4.8
	Different condition	2	3.0	7	8.3
	Influences by others	2	3.0	0	0.0
Physical environment and people’s attitudes	Disability due to environment factors	4	6.1	8	9.5
	Special environment	1	1.5	0	0.0
	Surrounding people’s attitudes and behaviours	0	0.0	21	25.0
	Reasonable accommodation and appropriate assistive technology	0	0.0	2	2.4
Interaction between impairments and environment	Interaction between impairments and environment	0	0.0	5	6.0
Discrimination, rights and participation	Restriction of participation, independent living	14	21.2	16	19.0
	Discrimination and disability in society	1	1.5	16	19.0
	Restrictions on rights and inadequate legal system	0	0.0	5	6.0
Total		66	100.0	84	100.0

Note: Some cases have more than one item per person because of the categorisation of each clause.

An additional analysis, the intrapersonal comparison, was performed using the same data source. After the classification of a dominant type of disability model per person, the researchers calculated the number of transitional-type cases. Whilst the number of persons whose description was classified into the 'individual or religious' model was the highest before DET (71.1%), the percentage of persons whose description was classified into the 'social' model was the highest after DET (68.9%). The percentage of those whose description transitioned from 'individual or traditional/religious' or 'other' models to the 'social' model was the highest (60.0%), whilst the percentage of those whose description was in line with the 'social' model and remained as such was 6.7%.

The following case is an example of an intrapersonal transition from the religious model before DET to the social model after it.

(Case 1)

BEFORE: (Disability is) a kind of a lack of organs and health that humans should have, given by God.

AFTER: (Disability is) an issue, due to some environmental conditions, which people face when they participate in society.

Before participating in DET the description was one of mixed religious and individual (medical) models. Following DET, possibly due to the focus on environmental issues, the description changed to what could be the social or the interactional model of disability.

Participants' descriptions that transitioned from the individual model to the social model are illustrated by the following cases.

(Case 2)

BEFORE: (Disability is) when intellectual and physical development is below the normal development.

AFTER: (Disability) relates to our understanding and view of other people.

(Case 3)

BEFORE: (Disability is) when a person cannot use his/her functions by himself/herself.

AFTER: (Disability is) a situation in which a person who has physical and mental impairments cannot equally and fully participate in society, by comparison to a person without disability, due to the individual and social view, a lack of communication, and physical barriers.

(Case 4)

BEFORE: (Disability is) physical and mental disabilities, and those who cannot participate in society freely due to these disabilities.

AFTER: (Disability is) 1) discrimination and environment, 2) restricted equality and human rights.

Before DET these descriptions were focused on insufficient development at the individual level, in comparison to other people; they can be classified into the individual or the medical model. By contrast, after DET the descriptions focused on the association with social barriers, represented by the use of the term 'our' or the public's understanding of and perspectives regarding disability. They can be classified into the social or the interactional model because the relationship within adequate public awareness, including the participant's attitude, is a social barrier.

Similarly, the expression of being inferior, worse or incapable was observed in the descriptions given by four participants before attending DET, which then transitioned from the individual model to the social or interactional model after DET.

RESULTS IN PHASE TWO

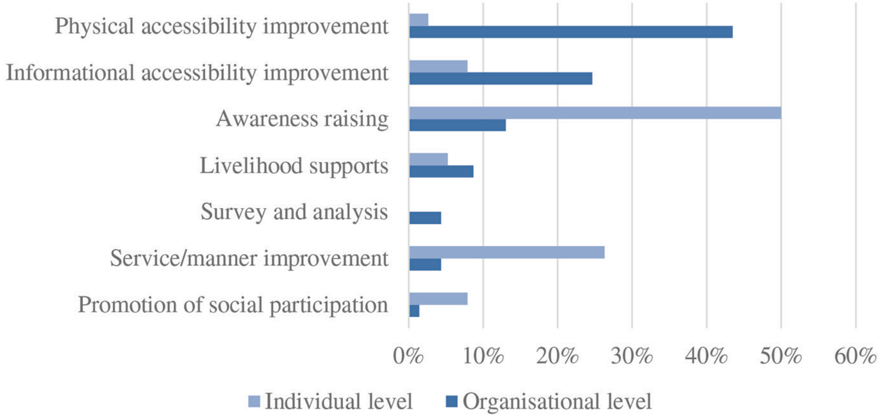
The Degree and Factors of Changing Behaviours after a DET Session (3rd level)

Among the interviewees, 89.7% self-reported a change in their attitudes towards disability and 76.9% reported taking actions related to inclusion. Figure 2 shows the cases of actions reported by the interviewees at organisational and individual levels after DET sessions. The data does not show the percentage of all DET participants in Ulaanbaatar but indicates the tendency within the selected sample to change their attitude and behaviours.

Regarding the results for the individual-level behavioural changes after DET sessions, 'awareness raising' was in the majority (with half of the total cases), followed by 'service/manner improvement' (at 26%). Within the 'awareness raising' category, teaching close friends and families and continually promoting disability understanding were present in six cases each. In the 'service/manner improvement' category, appropriate practice in the field was the sub-category encountered the most (four cases).

In terms of behavioural changes at the organisational level, accessibility improvement (sum of physical and informational) was the highest (at 68%), followed by 'awareness raising' (at 13%). In the 'physical accessibility improvement' category, refurbishment of the parking area was the highest (seven cases), followed by the establishment of a ramp and clearance of steps (five cases). In the 'informational accessibility improvement' category, allocation of sign language interpreters was the highest (six cases).

Figure 2: Categorisation of Actions taken at Individual and Organisational Levels



Note: Cases that contained any actions at the individual level (n = 31) and organisational level (n = 34) were extracted. The data includes plural cases that one participant self-reported.

The Perceived Impact (4th level)

During the interviews and field visits, the researchers observed several cases which indicated that the participants' attitude and behaviour changes after DET sessions impact society and individuals. They were identified by reviewing the self-reported good practices and visiting the actual sites.

First, some interviewees reported the general feedback from customers, including *"we heard that toilets have become easier to use"* (P3) and *"Doors have become lighter so* *that they are easier to open"* (P7). Furthermore, organisers (P12) of the 4th Asia-Pacific Community-Based Inclusive Development (AP-CBID) Congress in 2019, whose preparation training included DET, showed a quite positive overall evaluation done by participants, including the satisfaction with transfer and guidance.

Second, some interviewees mentioned usage situations and the emergence of the voices of disabled people. Although the direct causal relationship with DET sessions was unclear, a library staff member (P1) felt that the number of users who are disabled people had increased recently, and other interviewees (P28, P31, P32) stated that the frequency of seeing disabled people outside in the city had also increased.

In another case in the government sector, after DET sessions a district office of social insurance improved the environment of the medical and labour examination committee. The staff members heard the voices of disabled persons who said they would avoid having to do an application procedure twice in different places (P9).

In the private sector, the management staff of a mega telecom company (P24) reported that after DET sessions they commenced the new activity of hiring disabled persons, in cooperation with the General Authority for Development of Persons with Disabilities where a DET facilitator works. Consequently, up to this study's interview date, approximately seven disabled persons had applied for job opportunities. The company simultaneously requested seminars or training from the government sector and DPUB to create a decent work environment and reasonable accommodation.

Third, some interviewees pointed out the staff attitudinal changes towards disability and disabled people. A staff member from a government institution reported,

> *"Before holding seminars, including DET, some staff members felt that they didn't want to touch and come into contact with persons with disability, giving them a displeased feeling. But now I don't hear such kind of talks from our staff."*

Some interviewees from private companies stated that staff members, including those who did not participate in DET, at the organisation level got interested in a barrier-free environment and universal designs. The manager of a hotel company (P10), for instance, visited the good practice cases regarding universal designs and considered applying such an environment. Another person, a bank manager (P14), reported that he intentionally expanded the actions within a branch office, including the creation of a priority reception support for those in need.

Fourth, some participants mentioned the impact of sharing the social model view of disability with others, particularly in educational settings. For instance, an interviewee who was concurrently working as a teacher (P18), attempted to convey the meaning of disability based on the DET perspective in her classroom. She felt that the understanding in the class had increased. Similarly, a lecturer from the Mongolian State University of Education reported that DET had contributed to the understanding on disability and motivation to learn among students, some of whom took modules on inclusive education.

Fifth, other interviewees narrated how DET impacted their own perspectives in life. A volunteer for the AP–CBID Congress who is a student stated,

> *"DET impacted me very much. I am now considering my future career, like working in a related field."*

Furthermore, two disabled persons who participated in DET (P26, P31) decided to apply for a DET training of facilitators a few months later. As DET facilitators, both of them would like to make a positive contribution to disseminate knowledge based on the social model of disability.

Exploring Factors associated with Behavioural Changes in Participants

Quantitative analysis

The factors connected with behavioural change at the individual level are shown in Table 2. A weak correlation ratio overall ($\eta^2 = 0.28$) was found. The individual attitude changes had a relatively stronger positive correlation with non-disabled persons and those under the age of 30.

Using the same data, the researchers analysed the factors related to behavioural changes at the organisational level (Table 3). A weak correlation ratio overall ($\eta^2 = 0.31$) was found. In addition to the change in participants' attitudes, a specific type of DET session, namely the 3-hour session with other interventions, contributed to the organisational actions.

Table 2: Multivariate Discrimination Analysis of Behavioural Changes at the Individual Level after DET Sessions (n = 39)

Item	Category	Score	Range
Disabled person	Yes	–1.75	1.98
	No	0.23	
Gender	Male	–0.09	0.12
	Female	0.03	
Age (years)	< 30	0.77	1.78
	30–39	0.04	
	> 40	–1.01	
Times of attending DET session	1 time only	–0.19	0.68
	More than twice	0.49	
Type of DET session	3 hours	0.10	0.37
	1 and a half hours	–0.15	
	3 hours and other interventions	0.22	
Experience of interaction with disabled person(s) (before DET)	Yes	–0.51	1.18
	No	0.68	

Note: Correlation ratio $\eta^2 = 0.28$

Table 3: Multivariate Discrimination Analysis of Behavioural Changes at the Organisational Level after DET Sessions (n = 39)

Item	Category	Score	Range
Times of attending DET session	1 time only	–0.06	0.22
	More than twice	0.16	
Type of DET session	3 hours	–0.61	1.72
	1 and a half hours	–1.07	
	3 hours and other interventions	0.65	
Participation in DPUB activities	Yes	0.30	0.53
	No	–0.23	
Change of attitude after DET	Yes	0.19	1.67
	No	–1.48	
Positional level	Manager and higher	0.11	0.26
	Others	–0.15	

Note: Correlation ratio $\eta^2 = 0.31$

Qualitative analysis

Promotional factors at the individual level

This main theme associated with promotion of behavioural changes after DET was divided into two sub-themes: 'Readiness of the individual' and 'Attitude changes relying on conditions of DET'.

The 'Readiness of the individual' represents the perspectives and experiences of those who participate in DET. A female participant (P4), who has a sister with impairments and was facing difficulties, was hopeful of solving the issues in society even before participating in DET. This does not mean, however, that only those who had made plans in advance were inspired to take action. A participant who had not interacted with disabled people before DET (P12), said that he was stimulated by DET facilitators in the session, like *"electric shocks"*, to adopt a new perspective regarding disability.

'Attitude changes relying on conditions of DET' is related to the objectives of DET to change participants' attitude and behaviours towards disability issues. The project manager of DPUB (P33) explained,

> *"Because DET has been integrated into any disability-related seminars and workshops, participants can learn the basic view on disability. Based on such common understanding, we can discuss the next steps that should be taken together."*

However, as mentioned earlier, participants have different training experiences in varying conditions, such as the time framework (one and a half hours or 3 hours) and contents, set training or not, the number of times participating in DET (the first time or not), and interaction with group members, among others. A library staff member (P1), for example, expected to receive support training for disabled people instead of DET, but she noticed that the DET session formed a basis for the set training to gain perspectives regarding disability in society. Furthermore, a government officer (P4) said that participants, including her, could discuss concretely what actions the government authority should take, by following a set training of DET with an accessibility check. In other examples, participants who undertook DET more than twice (P18, P28), reported that they were able to have a better understanding of the meaning and implications, such as discovering different barriers and coming up with new ideas for actions, after re-watching the video material 'Talk' in the second session.

Some participants mentioned the different quality of each DET session. A government officer (P4), who participated in DET sessions twice, pointed out the possibility that the extent of influence and learning in DET would vary depending on the skills of the facilitators. A DET trainer (T1) explained that because of the obvious differences in competency and skills between facilitators, the DPUB has conducted follow-up training continually for them.

Promotional factors at the organisational level

Within-organisation dynamics and compatibility form a theme associated with actions taken as a member of an organisation. It is divided into the following sub-themes: 'Promotion of a key person's understanding', 'Participation as an organisation', 'Compatibility with an organisation's momentum and timing', and 'Budget arrangement'.

The 'Promotion of a key person's understanding' includes cases in which those in charge of coordinating a DET session within an organisation functioned as mediators in taking organisational actions after the session. A senior officer of a government division related to transportation, for instance, played a substantial role in passing a policy plan for improvement of physical accessibility. Although her boss had not participated in DET, she submitted a draft plan to a related committee and facilitated its adoption. This case indicates the importance of participation of a key person within an organisation, who has authority and can play a coordination role for organisational actions.

A similar case is illustrated by a social policy section chief in a district in Ulaanbaatar (P28). She stated, *"There are many things which we can do without any budget"*, and has acted on her own initiative at a grassroots level, in cooperation with local stakeholders. She emphasised the importance of promoting the upper echelons' understanding of the social model of disability because the process of obtaining approval became smoother than before participation in DET and DPUB's activities. An officer in a human resources division in the same district (P29) reported her chief's practices. She said that the chief implemented activities for promoting public understanding of disability in the district and such follow-up activities after DET fostered understanding within the organisation.

The 'Participation as an organisation' sub-theme is related to the 'Promotion of a key person's understanding'. It includes cases where participation in DET of multiple members within an organisation, including the upper echelons, led to organisational actions. According to a chief of the General Authority for Social Insurance (P4), most of the staff in the headquarters participated in DET. She said it felt easier to discuss a new policy on accessibility and service improvement within the organisation because of the basic and common understanding among the staff. A similar situation was also identified in the private sector. For example, a hotel manager (P7) stated that the staff members, including her bosses, discussed ways of improving physical accessibility just after DET. According to her, her bosses finally decided to improve the physical and informational accessibility in the hotel.

The 'Compatibility with an organisation's momentum and timing' sub-theme, although it overlaps with the above sub-themes, is the relationship between the timing of an implemented DET session with an organisation's condition of readiness. It includes implementation at the time of planning the year's activities within the organisation, when upper management and the head of an organisation changed, and when administrative instructions for improvement measures were given, among others. It is exemplified by the branch manager of a major bank (P14), who explained that DET was implemented at the time when the company's top management was changed and new policies were created. Although it is inappropriate to consider the causal relationship of DET with the bank's activities, he said that DET was one of the catalysts for promoting understanding of disability and the organisation's action.

A member of a youths' leadership training programme (P21) stated that a team had just discussed a plan regarding some social issues before participation in DET. Since they had attended other seminars on disability issues, this was at a time when their momentum to obtain in-depth understanding on the issues was on the rise. The association of DET with substantial actions was not clear in these cases, but DET became one of the factors that inspired organisations to tackle social issues.

Related to the 'Budget arrangement' sub-theme, some stakeholders attempted to negotiate with the government sector in charge in order to obtain the necessary funds. According to a manager-level staff of an airport (P10), after a DET session they made an official budget request to the ministry in charge through the Sub-commission of Rights of Persons with Disabilities that has been established under each ministry. By contrast, based on the explanation of practices and achievements in one district in Ulaanbaatar, some interviewees (P18, P28) emphasised the importance of actions such as renovation work, whether they have an adequate budget or not.

Barriers to taking an action

This main theme represents factors that prevented participants from taking actions based on the social model of disability, even though they had planned to do so after the session. It includes the following sub-themes: 'Limitation of budget and time', 'A lack of know-how and skills', 'Outside the scope of discretion and authority', 'Conflicting environment', 'Lack of organisational capacity' and 'Issues of DET implementation'.

In this main theme, the 'Limitation of budget and time' sub-theme is the most frequent barrier perceived by participants. An interviewee from a public institution (P3) stated,

> *"It is a good idea to renovate the inside facility, but we cannot allocate the huge amount of money. I think we need to think about the priority."*

A government staff member (P4) also stated,

> *"Actually, it is just a budget matter. What we can do is to improve the environment in the authority using the existing renovation budget."*

'A lack of know-how and skills' represents a situation in which participants wanted to act, but could not do so because of a lack of knowledge and skills. For example, a staff member of the public library (P1) stated that she would like to voluntarily make a software application of a digital accessible information system but did not know how to create it by herself (After the interview, the researchers introduced her to a person who knew how to create it).

'Outside the scope of discretion and authority' captures cases in which action was prevented due to regulations and rules within an organisation. A branch manager of a private company explained that the range of implementation by a branch office is defined by the headquarters. Therefore, the staff at the branch did what was possible within their discretion, such as renovating the entrance and main floor in order to improve physical accessibility. Also, an officer in the government sector stated that there are cases when they cannot proceed with the implementation of disability-inclusive policies, including the amendment of accessibility-related standards and rules, without official approval at the upper administrative levels.

The 'Conflicting environment' sub-theme indicates the possibility of a conflict that might arise from taking a particular action, as an advantage to one could cause inconvenience to another. A manager of a business hotel (P7) explained,

> *"We want to change carpets so that wheelchair users can move around in the hotel more easily, but we have not decided yet. Because some staff explained it would affect the use of other customers, we are on the process of discussion."*

Another example was provided by a section chief in a public institution (P12). He stated that the institution was now working towards introducing new facilities and they had to keep the renovation of the existing facilities at a minimal level.

The 'Lack of organisational capacity' sub-theme indicates an issue of capability development of some organisations, including Disabled People's Organisations. A manager of the social policy section in the local government sector (P28) suggested that capacity development in human resources and organisations regarding disability issues, as well as the promotion of social participation by disabled people, are required. According to her, the voices of disabled people are necessary in order to promote disability-inclusive activities, including planning, monitoring and evaluating. However, she felt that the social participation of disabled people has been quite limited, particularly in rural districts.

Some interviewees pointed out 'Issues of DET implementation' and offered suggestions for DET. As mentioned in the 'Attitude changes relying on conditions of DET' sub-theme, some participants felt that a one-time DET session was likely to be inadequate because they forget their perspectives regarding the social model of disability. According to a manager in the government sector (P9),

> *"DET is a very good measure, but it is one training session. As I review other participants' reactions, a one-time is not enough…A set training of DET with other training would also be nice."*

Other participants (e.g., P26) suggested some improvements, such as a follow-up DET for participants, a set training with more practical work, and a flexible schedule.

DISCUSSION

This study mainly aimed to examine the DET participants' attitude and behaviour changes in Ulaanbaatar, through their experiences in the local context. Using the framework of the four-level approach for training evaluation (Kirkpatrick & Kirkpatrick, 2006), together with mixed-methods, the authors attempted to analyse the degree of satisfaction with a DET session (1st level); the degree of attitude change, or gaining the perspective based on the social model of disability

(2nd level); the degree and factors of change in behaviour after a certain period of the DET session (3rd level); and the impact of the DET session as perceived by participants (4th level).

First, the descriptive analysis of the questionnaires collected just after DET showed a high degree of participants' overall satisfaction with the sessions. Second, the descriptive data analysis written by participants before and after the sessions revealed that most of them experienced a perspective change on disability, based on the social model. Third, the majority of interviewees, selected through purposive sampling, self-reported changing their attitudes and taking actions. Fourth, some cases illustrated a social impact of participants' actions after DET sessions. The impact ranged from a small to a relatively large scale, which was probably dependent on their living and working environments.

In terms of factors associated with the actions taken by participants after the session, the multivariate discrimination analysis identified that a set session of 3 hours of DET with other interventions has a relatively high partial correlation coefficient (A negative correlation ratio between the change in perspective and action-taking on one side, and the participants among the disabled persons on the other, was observed. Those who had already gained perspectives regarding the social model before attending DET might have affected the analysis in the small sample size). The qualitative analysis also implied relationships with the other promotional factors of taking actions at the organisational level, such as the coordination with key persons in organisations with an intention of conducting DET sessions, and the authority to implement any changes.

These findings suggest that a certain version of DET sessions is most likely to lead to actions and change. As Igei (2020) reveals in South Africa, the findings of this study support the importance of integrating DET with other interventions and conducting DET in cross-cutting sectors. Some participants, for example, implied that they were able to take actions because they also participated in and learnt from other activities, such as an accessibility check in society, and service and manner training based on the reasonable accommodation perspective. Indeed, the context of implementing DET sessions varies in Ulaanbaatar; some DET sessions, for example, were independently conducted and other DET sessions were integrated with seminars and workshops for various stakeholders, not only from the government sector but also from non-governmental and business sectors. Therefore, there would be room for re-examining the overall plan and vision of DET in the Mongolian context.

The findings of the study, in particular from thematic analysis, also indicate that even if participants learnt the view of the social model of disability in DET sessions, their subsequent actions depended on promotional factors and barriers at the individual and organisational levels. DET manuals for its facilitators and trainers (Gillespie-Sells & Campbell, 1991; Carr et al, 2012; Kuno, 2018) explain how to conduct DET and its fundamental perspective (the social model of disability and human rights), but the present findings suggest the importance of assessing and monitoring the situations and reality of participants, including organisational and environmental barriers, after taking part in sessions. This means that DET sessions could be adjusted after considering the tendencies and contexts of participant groups through pre-interviews and post-interviews (or consultations) with them.

Implications

The findings of this exploratory study carry implications for policy and practice. Two main implications are emphasised, namely, the significance of DET sessions and the issue of DET sustainability. First, the findings support DET as a powerful measure to promote disability-inclusive policies and practices in line with the social model of disability in Ulaanbaatar. Since this project aimed to promote the social participation of disabled people by removing barriers in society, DET based on the social model matched it well. Although many models of disability exist, such as the charity model, the medical model and the human development model (Marks, 1997; Mitra, 2018), the findings indicate that DET can be used to foster a common view based on the social model and human rights, and to promote changes of the social environment through voluntary actions taken by the participants as agents of change (Carr et al, 2012).

Second, one of the critical issues of DET, which was technically supported by donor organisations, is related to sustainable development in the local context. The system of continually conducting and developing DET must be secured. In other words, if DET does not continue substantially after the end of the technical cooperation project in Ulaanbaatar, the impact of DET on society may be limited in the future. There are some possibilities of conducting DET regarding an implemented entity and budget, exemplified by individual DET facilitators, business and non-government organisations (such as DET forum) which earn income from participation fees and subsidisation, and the government sector which hires DET facilitators directly. Hence, a critical re-examination of the system and situation would be significant.

Limitations

This study has several limitations related not only to methods but also to the theoretical analysis. Since the selected sample and applied methods differed between Phase one and Phase two, careful interpretation is required. Cases selected by purposive sampling would be expected to show better practices than those who were not selected. Therefore, the findings cannot be generalised with exaggeration of good practice cases of Phase two.

Second, a critical view on the methodology and findings is also fundamental. DET, which is conducted by disabled people, has become a social movement with a radical philosophy (Millington & Mottram, 1999). In addition, Kuno (2018) argues that DET has been influenced by Paulo Freire’s pedagogy, such as critical consciousness. This means that an evidence-based approach, considering objective findings over the impact of such a critical practice and social movement, could cause a conflict or a kind of power relationship between the narratives of DET stakeholders and academic discourses of researchers. Hence, continuing a critical debate on impact evaluations and related studies is suggested.

CONCLUSION

Notwithstanding its preliminary character and limitations, this paper advances studies on DET in natural field settings. Participants’ attitude changes in line with the social model of disability, and actions taken by individuals and organisations were clearly identified. In addition, this study has findings and implications that have not hitherto been highlighted by the prominent papers on DET, including DET manuals. For instance, the contexts and possible factors of participants’ attitude and behaviour changes seemed to be complicated. This indicates that stakeholders of DET sessions, such as DET facilitators, need to consider the background of each participant, ranging from personal motivations to their organisational environments. The findings also showed the implications for conducting DET sessions in the Mongolian context. The findings emphasised the importance of strategic implementations of DET, including considerations regarding DET forms and other additional interventions in each unique context.

It is therefore suggested that future studies should examine the effectiveness of a strategy by considering the factors identified in this study and by using a reliable sample in various settings where DET sessions are conducted.

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Characteristics of Outpatients receiving Physical Therapy Services at a Provincial Hospital in Papua New Guinea: A Descriptive Case Study

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ABSTRACT

Purpose: *Development of Physical Therapy (PT) services for people with disability is one of the urgent challenges in the health sector in Papua New Guinea (PNG). However, information on the current status of PT services in PNG is scarce, as also is the case for the hospital-based outpatient PT services. This study aimed to describe the characteristics of outpatients receiving PT services in a provincial hospital in West New Britain (WNB) Province, PNG and to compare them with the characteristics of inpatients.*

Method: *This was a retrospective case study using outpatient and inpatient records. The records of clients receiving PT services as either outpatients (413 records, outpatient group) or inpatients (350 records, inpatient group) were reviewed in relation to sex, age and diagnosis. Comparisons were made between the two groups on basis of quantitative data of the two patient groups .*

Results: *The final analysis comprised 404 records in the outpatient group and 344 records in the inpatient group. In the outpatient group, injury and musculoskeletal disease were forming the most dominant diagnosis groups with 52.5% and 22.0%, respectively. Injury was most common in the age group 20 to 39 years and musculoskeletal diseases was most common in the age group 40 to 59 years. These two diagnosis groups and congenital malformations were significantly more represented among outpatients than among inpatients.*

Conclusions: *Young to middle-aged clients with injury or musculoskeletal disease were predominant among outpatient PT services as compared to*

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inpatient services. The study findings serve to provide information on the current situation and potential needs of hospital-based outpatient PT services in one provincial hospital of PNG. These findings could be the base for planning outpatient PT service in WNB Province and PNG.

Key words: *Papua New Guinea, physical and rehabilitation medicine*

INTRODUCTION

Papua New Guinea (PNG), with an estimated 8 million people speaking 841 different languages (World Health Organisation, 2016), is a country located in the Western Pacific that is renowned for its environmental, cultural and biological diversity (National Statistical Office PNG, 2015). The majority (88%) of the population lives in rural areas, with the remaining 12% living in urban areas (National Statistical Office PNG, 2015). Papua New Guinea, experiencing constant economic growth against a backdrop of large-scale developments of mineral and gas resources (Jubilee Australia, 2018), is categorised as a lower-middle-income country according to the World Bank criteria (The World Bank, 2019).

However, some of the health-related statistics of PNG are similar to those of low-income countries (World Health Organisation, 2014). The burden of disease in PNG is largely dominated by communicable diseases such as pneumonia, tuberculosis and diarrhoeal diseases, but the prevalence of non-communicable diseases (NCDs) such as diabetes and ischaemic heart disease is rapidly increasing (World Health Organisation, 2016).

In this health situation, disease-induced disabilities are some of the urgent health-related challenges for the health sector, requiring attention for well-functioning rehabilitation services which are integral to improving the health of people with disability in PNG (Papua New Guinea Ministry of Health, 2010a). Rehabilitation is a set of multi-disciplinary interventions designed to optimise functioning and reduce disability in individuals with health conditions in interaction with their environment (World Health Organisation Regional Office for the Western Pacific, 2019). Physical therapy (PT) is a medical rehabilitation service which is included in the Papua New Guinea National Health Plan 2011-2020 (Papua New Guinea Ministry of Health, 2010a) and is regarded as an important countermeasure to reduce morbidity and prevent early mortality from non-communicable diseases.

Since 2008, PT education at a Bachelor level has been offered in PNG (Karthikeyan and Ramalingam, 2014). However, the PT workforce in PNG is small, with the number of physical therapists estimated to be approximately 70 (World Confederation of Physical Therapy, 2019). Moreover, information on the current PT services in PNG is scarce (Berg, 1976; Brogan, 1982; Powell, 2001; Shaw, 2004; Saito et al, in press). To encourage the development of the PT profession in terms of both quality and quantity, and to mitigate the disability-related burden, a critical starting point would be to clarify and share knowledge on the current status of PT.

Rehabilitation services including PT in PNG are mainly provided as institution-based services (Shaw, 2004). Few studies on hospital-based inpatient PT services are available (Berg, 1976; Brogan, 1982; Powell, 2001; Saito et al, in press). According to the authors' knowledge, only one report on outpatient PT services has been published (Powell, 2001). Powell (2001), using audit data on medical conditions of inpatients and outpatients receiving PT services in a provincial hospital in PNG, reported that neurological conditions were the most common medical conditions among inpatients while it was musculoskeletal pain among outpatients. This report (Powell, 2001) implied that there might be some differences in the characteristics and PT needs between inpatients and outpatients, and focusing on outpatients would provide unique insights into the current situation of PT services in PNG.

In Powell's study (2001), medical conditions were classified and described on the basis of the clinical manifestations, such as 'chest conditions', 'neurological conditions' and 'orthopeadic conditions'. Hence, information on specific medical diagnoses was not available. Moreover, clients were described as either being a 'child' or 'adult', and thus, demographic information was not available (Powell, 2001). Data on medical diagnoses and demographics is essential to gain a better understanding of the current situation and needs regarding PT services in PNG. This data could be useful to policy makers in planning the provision of outpatients PT services in PNG.

Objective

The objectives of this study were to describe the characteristics of clients receiving hospital-based outpatient PT services and to highlight their characteristic features by comparing them with those of inpatients so that the evidence could be used for planning the provision of PT service in PNG. The hypotheses, which was formulated on basis of the findings of previous studies (Powell, 2001; Saito et al, in press), assumed that medical diagnoses relating to orthopaedic medical conditions in the young to middle-aged generation would be dominant among outpatients, and there would be significant differences in terms of diagnosis and age group between outpatients and inpatients.

METHOD

Study Design

This was a retrospective case study, using outpatient and inpatient records. The data was collected as part of a research project that explored optimal methods of international cooperation on physical therapy services in PNG.

Study Setting

The study was conducted at Kimbe Provincial Hospital of West New Britain (WNB) Province, PNG. This hospital, which has 180 beds for inpatient care, is the single hospital in WNB Province that provides secondary and tertiary medical services, including inpatient services, outpatient services and community outreach services. Further details on the study setting and study participants can be found in an earlier written – yet unpublished report (Saito et al, in press).

Data Collection

The authors reviewed the records of all clients who received outpatient PT services (Outpatient group) from the 1st of August, 2016, to the 31st of October, 2018; as complete data was available only for this period. These records included data on clients' sex, age and diagnosis. Data items were categorised as follows: sex (female, male); age (<1 year old, 1–4 years old, 5–19 years old, 20–39 years old, 40–59 years old, and ≥60 years old); and diagnosis based on the ICD version 10 (International Classification of Diseases Ver. 10 - ICD-10 code of World Health Organisation, 2019). Data on diagnosis comprised of the medical condition (i.e. the disease) or the disability as relevant to PT services. When names of disability were described and classifications were not completely according to ICD-10 codes, the authors checked the detailed client chart and specified medical conditions and then converted them into the appropriate ICD-10 code.

The authors used data on the characteristics of clients receiving inpatients PT services in Kimbe Provincial Hospital (Inpatient group) that were described in their previous study (Saito et al, in press). The same data collection methodology and recruitment period were used in both the outpatient and the inpatient groups to ensure that clients' characteristics were comparable between the two.

Exclusion Criteria

During the study's recruitment period, some outpatients and inpatients either restarted or were readmitted for PT services under the same diagnosis. To avoid multiple counting, only the records of the initial utilization of service were included; records of the readmission or restarted outpatient PT services were excluded from the statistical analysis.

Data Analysis

Categorical variables are reported as number and percentages. The clients' characteristics and the diagnosis data were categorised by sex, and the Chi-Square test was used to compare the characteristics between the outpatient and inpatient groups. A two-tailed P value of <0.05 was considered to indicate statistical significance. Statistical analyses were performed with IBM SPSS Statistics (Version 22, IBM Japan Ltd.).

Ethical Consideration

This study was approved by the clinical service directorate of Kimbe Provincial Hospital. All data was kept confidential. As this was a retrospective study, the requirement for informed consent from clients was waived.

RESULTS

In this retrospective survey, 413 records in the Outpatient group and 350 in the Inpatient group were investigated. In the Outpatient group, 9 records were excluded because the clients had restarted outpatient PT services, so 404 records was the final number analysed. In the Inpatient group, 3 records were excluded because of client readmission and another 3 records because of missing data, so 344 records was the final number of records analysed.

Characteristics and Specific Diagnosis by Sex

Characteristics of participants and specific diagnoses in the Outpatient group are shown in Tables 1 and 2, respectively. In Table 1, specific names of the diagnosis groups accounting for 5% and more of the diagnoses in the Outpatient group are listed; the diagnoses with less than 5% representation are merged into the category ‘others’.

Among the clients, the 20 to 39 year age group was the most dominant for both sexes and both groups. Approximately 60% in the Outpatient group and 65% in the Inpatient group were 40 years old or younger.

The five dominant diagnosis-related groups among the Outpatients were injury (ICD-10 codes: S00-S99 and T00-T88), musculoskeletal disease (ICD-10 code: M00-M99), infectious disease (ICD-10 code: A00-B99), congenital malformations (ICD-10 code: Q00-Q99) and circulatory diseases (ICD-10 code: I00-I99) (Table 1). Overall, 52.5% of the outpatients’ diagnoses were due to injury, 22.0% due to musculoskeletal disease, 7.20% due to infectious disease, 6.20% due to congenital malformations, and 5.70% due to circulatory disease (Table 1).

Table 1: Participants’ Characteristics

	Outpatient group			**Inpatient group**		
	Female (n=164)	Male (n=240)	Total (n=404)	Female (n=127)	Male (n=217)	Total (n=344)
	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
Age (years)						
<1	4 (2.40)	7 (2.90)	11 (2.70)	11 (8.66)	11 (5.07)	22 (6.40)
1 to 4	16 (9.80)	16 (6.70)	32 (7.90)	23 (18.1)	24 (11.1)	47 (13.7)
5 to 19	27 (16.5)	38 (15.8)	65 (16.1)	20 (15.8)	38 (17.5)	58 (16.9)
20 to 39	60 (36.6)	78 (32.5)	138 (34.2)	37 (29.1)	57 (26.3)	94 (27.3)
40 to 59	41 (25.0)	74 (30.8)	115 (28.5)	28 (22.1)	56 (25.8)	84 (24.4)
≥60	16 (9.80)	27 (11.3)	43 (10.6)	8 (6.30)	31 (14.3)	39 (11.3)
Diagnosis						
Injury	83 (50.6)	129 (53.8)	212 (52.5)	21 (16.5)	69 (31.8)	90 (26.2)
Musculoskeletal diseases	43 (26.2)	46 (19.2)	89 (22.0)	14 (11.0)	10 (4.61)	24 (7.00)
Infectious diseases	11 (6.70)	18 (7.50)	29 (7.20)	50 (39.4)	65 (30.0)	115 (33.4)
Congenital malformations	10 (6.10)	15 (6.30)	25 (6.20)	3 (2.40)	3 (1.40)	6 (1.70)

Circulatory diseases	3 (1.80)	20(8.30)	23 (5.70)	12 (9.45)	32 (14.8)	44 (12.8)
Others	14 (8.50)	12 (5.00)	26 (6.40)	27 (21.3)	38 (17.5)	65 (18.9)

The two most dominant diagnoses in each of the five diagnosis-related groups were fracture and 'dislocation and sprain of joint' in injury; pain and arthritis in musculoskeletal disease; 'tuberculosis-related disease' and poliomyelitis in infectious diseases; 'congenital deformities of feet' and microcephaly in congenital malformations; and 'cerebrovascular disease' and hypertension in circulatory disease (Table 2). Of the 21 outpatients with congenital deformities of the feet, 14 had congenital talipes equinovarus (CTEV).

Table 2: Diagnosis of the Outpatients Receiving PT Services (by Sex)

	Female (n=164)	Male (n=240)	Total (n=404)
	n (%)	n (%)	n (%)
Injury			
Fracture	38 (45.8)	67 (51.9)	105 (49.5)
Dislocation and sprain of joint	27 (32.5)	33 (25.6)	60 (28.3)
Wound or injury	15 (18.1)	29 (22.5)	44 (20.8)
Burns	2 (2.41)	0 (0)	2 (0.94)
Injury of nerves and spinal cord	1 (1.20)	0 (0)	1 (0.47)
(Subtotal)	83 (100)	129 (100)	212 (100)
Musculoskeletal diseases			
Pain - back pain	11 (25.6)	16 (34.8)	27 (30.3)
Pain - except back pain	10 (23.3)	8 (17.4)	18 (20.2)
Arthritis	7 (16.3)	4 (8.70)	11 (12.4)
Adhesive capsulitis	3 (6.98)	2 (4.35)	5 (5.62)
Others	12 (27.9)	16 (34. 8)	28 (31.5)
(Subtotal)	43 (100)	46 (100)	89 (100)
Infectious diseases			
TB - Other parts of the body	3 (27.3)	8 (44.4)	11 (37.9)
TB - Meningitis	4 (36.4)	4 (22.2)	8 (27.6)
Respiratory TB	1 (9.09)	5 (27. 8)	6 (20.7)
Acute poliomyelitis	3 (27.3)	1 (5. 6)	4 (13.8)
Others	0 (0)	0 (0)	0 (0)
(Subtotal)	11 (100)	18 (100)	29 (100)
Congenital malformations			

Congenital deformities of feet	9 (90.0)	12 (80.0)	21 (84.0)
Microcephaly	1 (10.0)	2 (13.3)	3 (12.0)
Others	0 (0)	1 (6.67)	1 (4.00)
(Subtotal)	10 (100)	15 (100)	25 (100)
Circulatory diseases			
Cerebrovascular accident	3 (100)	19 (95.0)	22 (95.7)
Hypertension	0 (0)	1 (5.00)	1 (4.35)
(Subtotal)	3 (100)	20 (100)	23 (100)

TB = tuberculosis

Number of Outpatients among the Five Diagnosis-related Groups (by Age Group)

Table 3 shows the numbers and percentages of each age group among the five dominant diagnosis-related groups. Overall, the dominant age group in injury was the young group (20 to 39 years old). The middle-aged group (40 to 59 years old) accounted for most of the clients with musculoskeletal disease, the adolescent to infant group (less than 20 years old) accounted for most clients with infectious diseases, the infant age group (below 5 years) accounted for clients with congenital malformations, and the middle- and senior-age group (40 years and older) accounted for the majority of clients with circulatory diseases.

Table 3: Numbers and Percentages of Outpatients among the Five Diagnosis Groups (by Age Group)

	<1 year old	1 to 4 years old	5 to 19 years old	20 to 39 years old	40 to 59 years old	≥60 years old
	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
Injury	1 (0.47)	5 (2.36)	38 (17.9)	99 (46.7)	57 (26.9)	12 (5.66)
Musculoskeletal diseases	0 (0)	0 (0)	5 (5.62)	28 (31.5)	44 (49.4)	12 (13.5)
Infectious diseases	1 (3.45)	5 (17.2)	11 (37.9)	6 (20.7)	4 (13.8)	2 (6.90)
Congenital malformations	8 (32.0)	14 (56.0)	3 (12.0)	0 (0)	0 (0)	0 (0)
Circulatory diseases	1 (4.35)	0 (0)	0 (0)	2 (8.70)	8 (34.8)	12 (52.2)

Comparison between Characteristics of Outpatients and Inpatients

Table 4 lists the results of the comparative analysis between the two groups, which showed significant differences in age and diagnosis (Table 4). Overall, the Outpatient group included a significantly higher number of clients in the 20 - 39 years age group, and in the diagnosis groups of injury, musculoskeletal disease and congenital malformations, than the Inpatient group. In contrast, the Inpatient group included a significantly higher number of clients in the below 5 years age group, and in the diagnosis groups of infectious disease and circulatory diseases, than the Outpatient group.

Table 4: Characteristics of the two Groups and results of Chi-Square Tests

	Outpatient group (n=404)	**Inpatient group (n=344)**	**Chi-Square value**	***P-value***
	n (%)	n (%)		
Age (years)				
<1	11 (2.70)	22 (6.4)†	**15.6**	**0.008**
1 to 4	32 (7.90)	47 (13.7)†		
5 to 19	65 (16.1)	58 (16.9)		
20 to 39	138 (34.2)†	94 (27.3)		
40 to 59	115 (28.5)	84 (24.4)		
≥60	43 (10.6)	39 (11.3)		
Diagnosis				
Injury	212 (52.5)‡	90 (26.2)	**169.2**	**< 0.001**
Musculoskeletal diseases	89 (22.0)‡	24 (7.00)		
Infectious diseases	29 (7.20)	115 (33.4)‡		
Congenital malformations	25 (6.20)‡	6 (1.70)		
Circulatory diseases	23 (5.70)	44 (12.8)‡		
Others	26 (6.40)	65(18.9)‡		

† The adjusted residual values were significantly high among outpatients of one age group (20 to 39 was 2.0) and among inpatients in two age groups (<1 was 2.4, 1 to 4 was 2.5). ‡ The adjusted residual values were significantly high among outpatients of three diagnosis groups (Injury was 7.3, Musculoskeletal disease was 5.7 and Congenital disease was 3.0) and among inpatients in three diagnosis groups (Infection was 9.1, Circulation disease was 3.4 and Others was 5.2).

DISCUSSION

The characteristics of 404 consecutive outpatients receiving PT services were reviewed and compared with those of inpatients. In the Outpatient group, the common diagnosis-related groups and their dominant age groups were injuries in the young age group (20 to 39 years) and musculoskeletal disease in the middle-aged group (40 to 59 years). These two diagnosis-related groups and congenital malformations were significantly more prevalent among the outpatients than the inpatients. The study results supported the proposed hypothesis that medical diagnosis relating to an orthopaedic medical condition in young to middle-aged clients would be dominant among outpatients and that there would be significant differences between outpatients and inpatients. Our findings show the current situation of outpatient PT services in WNB Province. This data provides a rough estimation of potential outpatients PT service needs and could be the base for planning the provision of this service in WNB Province and PNG.

Injury and musculoskeletal disease, the dominant diagnostic groups in the young to middle-aged outpatients, accounted for approximately 75% of all diagnoses in the Outpatient group. They were significantly more prevalent than those in the Inpatient group. These findings were similar to the results of a previous study (Powell, 2001), showing that musculoskeletal pain and orthopaedic problems were common medical conditions, accounting for approximately 55% of all problems in outpatients receiving PT services.

In the current study setting, the outpatient PT services provided for clients with injury and musculoskeletal diseases included not only typical therapeutic exercises but also application of plaster of Paris as a non-operative conservative immobilisation technique for injured limbs due to fractured bones, sprained ligaments, and inflamed and infected soft tissues (Szostakowski et al, 2017). The authors speculated that a large proportion of outpatients with injury musculoskeletal disease might take advantage of the wide-ranging outpatient PT services offered.

According to the Papua New Guinea National Health Plan 2011-2020 (Papua New Guinea Ministry of Health, 2010a), injuries account for 11% of the total burden of disease, while the information on prevalence rates of specific musculoskeletal disease is not available. However, musculoskeletal disease, especially that of the lower back, is reported as one of the leading global causes of disability (GBD 2015 Disease and Injury Incidence and Prevalence Collaborators, 2015), and common pain conditions affect a large percentage of people in both developed and developing countries (Tsang et al, 2008). Hence, it would be possible to estimate that a potentially large number of people suffer from musculoskeletal disease in Papua New Guinea. The findings of the current study, at least in part, reflect the injury and musculoskeletal disease- related burden in PNG.

Congenital malformations accounted for 6.2% of the diagnosis groups in the outpatient group and were significantly more prevalent in the Outpatient group than in the Inpatient group. Approximately 90% of outpatients with congenital malformations were in the less than 5- years-old age group. Of the 25 outpatients with congenital malformations, CTEV, which is a condition present at birth in which the foot is in a rigid turned-in position (Smythe et al, 2018), was the most dominant specific condition, accounting for 56%.

The incidence rate of CTEV in PNG is relatively high (2.7 per 1000 live births per year) compared with that of a Western country, the UK (0.89–1.24 per 1000 live births per year) (Culverwell and Tapping, 2009). The Ponseti method, a conservative treatment method consisting of serial manipulations and specific casting along with or without an Achilles tenotomy, is generally accepted as the first choice for correction of CTEV and is the most popular approach (Zhao et al, 2014). In the current study setting, physical therapists apply this method to infant outpatients with CTEV, as one part of PT services, this might lead our findings. Congenital malformations, especially for CTEV among children, may be a characteristic health condition referred to outpatient PT services in PNG.

The two diagnosis groups of infectious diseases and circulatory diseases were significantly less prevalent in the Outpatient group than in the Inpatient group. Although the specific reasons for this discrepancy between the two groups are unclear, the authors speculate that several factors relating to accessibility of outpatient PT services, such as each client's physical condition, geographical condition and socioeconomic condition (Urimubenshi and Rhoda, 2011) might contribute to the study results. Further studies are needed to clarify the challenges and difficulties associated with access to outpatient services in Papua New Guinea.

Limitations

The present study has several limitations. First, in terms of the generalisation of the findings, the health-related statistics in each province or district in PNG are different (Papua New Guinea Ministry of Health, 2010b). Thus, the present findings in WNB Province might not reflect the characteristics of people living elsewhere in PNG. Additional studies that take into account nationwide probability samples are required to better understand the clients' characteristics of outpatient PT service in PNG. Second, it was not possible to gather detailed information on the clients' life in their communities and the provision of PT services locally. To better understand current hospital-based outpatient PT services, further information such as specific barriers or obstacles that hinder clients' participation and integration into their community, specific PT interventions to address a wide range of clients' difficulties, and outpatient service administration, should be examined. Third, PT is one part of rehabilitation services that comprise multi-disciplinary interventions (World Health Organisation Regional Office for the Western Pacific, 2019). Further studies examining collaboration and cooperation between outpatient PT services and other services or professions such as referral mechanisms and strategies for sharing clients' information with other professions, are needed to gain a better understanding of outpatient PT services in PNG.

CONCLUSION

We investigated the characteristics of 404 consecutive outpatients receiving PT services have been described. The findings indicated that injury in the young age group (20 to 39 years old) and musculoskeletal diseases in the middle-aged group (40 to 59 years old) were the most common diagnosis groups among them. These two diagnosis groups and congenital malformations were significantly more prevalent among the outpatients than the inpatients. The study findings provide information on current situation for outpatient PT services and allow us to make rough estimation of the potencial service needs of outpatient PT services. These findings would form an important basis for planning of outpatient PT services in WNB Province and PNG.

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People with Physical Disabilities playing Light Volleyball: A Qualitative Study in Hong Kong

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ABSTRACT

Purpose: *This study aimed at understanding the perceptions of people with physical disabilities regarding playing Light Volleyball (LVB), identifying the possible constraints and risks they might face while playing, and providing their suggestions for fine-tuning the Light Volleyball intervention programmes.*

Method: *Four focus group interviews were conducted with 17 participants who joined the Light Volleyball trial programme. The participants were 11 males and 6 females, with an average age of 53.5 years (SD=11.83 years). People with poliomyelitis (n = 15), spinal cord injury (n = 1), hearing impairment (n = 1) were included.*

Results: *Participants indicated improved reactivity and coordination, cooperation in team, happiness, and novelty in general as positive outcomes while playing Light Volleyball. They preferred to play in the seated position (i.e., sitting light volleyball - SLVB), and with simpler rules. They believed that their ability to play Light Volleyball was subject to their body constraints.*

Conclusion: *Sitting Light Volleyball can be one of the new physical activity options for future sport promotion among people with physical disabilities in the community. The effectiveness of playing Sitting Light Volleyball in enhancing health among people with physical disabilities needs to be studied in future.*

Key words: *adapted physical activity, special populations, physical impairments, focus group*

INTRODUCTION

In Hong Kong, the prevalence rate of people with physical disabilities has increased from 2.72% in 2007 to 4.47% in 2013, particularly the result of the

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increase in the ageing population (Census and Statistics Department, HKSAR, 2014). The World Health Organisation (2015) encourages the organisation of accessible health promotion programmes for people with physical disabilities. The benefits of engaging in regular physical activity (PA) are well recognised. However, people with physical disabilities tend to participate less in physical activity (de Hollander & Proper, 2018) and have poorer health status (e.g., they experience more cardiac diseases and diabetes) than their peers without disability (Rimmer et al, 2007; Reichard et al, 2011).

A study in Hong Kong, that examined sport participation among people with disabilities, revealed that there are few sports available to them. People with disabilities who were interviewed demonstrated that people with physical disabilities have fewer opportunities to participate in PA than people with intellectual disabilities (Home Affairs Bureau, HKSAR, 2016). The study identified a service gap to provide more types of sports or implement more physical activity interventions for people with physical disabilities in Hong Kong.

Sitting Volleyball (SVB), an official Paralympic sport, is particularly fast and explosive in movement (Di Palma & Molisso, 2017). Athletic ability and strength are generally required (Vute, 1999). Thus, SVB is a high-level competitive team sport demanding power and agility, which suits people with disabilities who have high sport competence.

LVB, using a bigger and lighter ball, is a relatively common PA for older adults in China (Sun, 2010). In 2018, Leung and colleagues conducted a LVB intervention among older adults, aged ≥60 years, in Hong Kong. LVB was found to be beneficial to older adults' physical and psychological health (Leung et al, 2018).The pilot intervention study suggested that future studies should investigate LVB in other populations with lower fitness levels (e.g., people with physical disabilities).

Objectives

Keeping in mind the higher physical competences (e.g., speed) needed while playing SVB, the potential health benefits of LVB for people with physical disabilities, and the service gap to provide people with physical disabilities in Hong Kong with more types of sport and PA interventions, this study aimed at:

a) Understanding the perceptions of people with physical disabilities regarding playing LVB;

b) Identifying the possible constraints and risks they might face while playing; and

c) Providing their suggestions for fine-tuning the LVB intervention programmes for people with physical disabilities.

METHOD

Study Design

This qualitative study used trial sessions and focus group interviews to understand the perceptions of people with physical disabilities regarding playing Light Volleyball and to identify the possible constraints and risks they might face while playing.

Participants

The study was conducted in June 2018, as part of the Sitting Light Volleyball (SLVB) intervention project. Before the intervention programme, two trial sessions of a LVB game were organised for persons with disabilities from a partnering non-government organisation (NGO). The NGO was responsible for recruiting participants through WhatsApp groups and advertisements in their bimonthly magazine. Seventeen participants (n=17) of the LVB trial programme were invited to join the study.

The inclusion criteria were:

(a) Those who spoke in Cantonese, and

(b) Participated in the LVB trials.

Among the 17 participants, there were 11 males and 6 females, with an average age of 53.5 years (standard deviation=11.83years). People with poliomyelitis (n = 15), spinal cord injury (n = 1), hearing impairment (n = 1) were included. Of the total number of participants, 70% had secondary school-level education and 24% had university-level education or above. All of them had no prior experience in playing LVB.

Procedures

Details of the trial runs were confirmed after the enrolment of participants. The participants were first given a briefing on the objectives of the study, their involvement, confidentiality, potential risks of participation, and their option to leave the study at any time. Two trial sessions of a LVB game were organised and the participants were free to play LVB either in their own wheelchairs or in the sitting position under the supervision of coaches from the related NGO. With the inputs from the stakeholders (including participants and the partner NGO), some suggested game characteristics and rules were discussed and subsequently modified.

Data Collection

After each trial session, the participants were divided into two small focus groups to conduct interviews for the purpose of (a) understanding the perceptions of people with physical disabilities regarding playing LVB, (b) identifying the possible constraints and risks they might face while playing LVB, and (c) providing their suggestions for fine-tuning the LVB intervention programmes for people with physical disabilities. Questions were asked in an interactive group setting where participants were free to talk with other group members. During this process, the researchers took notes to capture participants' characteristics and information about group dynamics. Typically, interviews lasted 45 minutes. An HKD$100 supermarket cash voucher was given to the participants to acknowledge their contributions to the study.

The first author, with a trained research assistant, acted as the focus group moderator. Focus group interview is frequently used as a qualitative approach to gain an in-depth understanding of social issues. This method aims to obtain data from a purposely selected group of individuals rather than from a statistically representative sample of a broader population. Focus group interview enables researchers to interview multiple respondents simultaneously (Babbie, 2011) and is widely used to identify consumer needs that will assist in the development of future intervention programmes (Halcomb et al, 2007).Given its convenience, speedy results, high face validity, and cost effectiveness, it is commonly applied to generate data because of its purposeful use of social interaction (Krueger, 1988; Merton et al, 1990; Morgan, 1996). Focus group interview was adopted in this qualitative study because LVB is a group-based activity, and information about the group dynamics in this activity can be well captured through focus group interviews.

Data Analysis

All the interviews were audio-taped and transcribed verbatim by a research assistant. The transcript was checked by another research assistant. All participants were assigned an identification number for data reporting. All transcripts were then analysed through inductive thematic analysis, which is for identifying, analysing, and reporting patterns (themes) within data (Frith & Gleeson, 2014). This analysis process included (1) data familiarisation, (2) generating initial codes, (3)collating codes into potential themes,(4) refinement and review of themes,(5) defining and naming themes, and (6) finalisation of themes (Braun & Clarke, 2006). Through discussion meetings at regular intervals, authors developed a thematic framework containing key themes. This framework was then applied to data analysis, though the themes were reviewed and modified in the aforementioned six phases.

Ethics

Through a cover letter stating the details of the study (e.g., aims and procedures), consent was obtained from the person-in-charge of the partner NGO serving people with physical disabilities in Hong Kong. Informed consent was obtained from all individual participants included in the study. They gave their consent and participated in four focus group interviews (in groups of four or five). All procedures performed in studies involving human participants were in accordance with the ethical standards of the University Institutional Review Board and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

RESULTS

Participants' Perceptions about Playing Light Volleyball

Improved reactivity and coordination, cooperation in team, happiness, and novelty were positive outcomes in general perceived by the participants who played LVB.

When asked how playing LVB could benefit their body, the participants gave different answers.

One participant said, *"It seems to improve my reactivity and coordination of my body and mind. In the longer run, I think it could enhance cooperation among team members."*

Another participant explained, *"I feel happy to play together."*

One of the participants echoed, *"It is my first time playing LVB. I feel good and fun-full. I will continue to play."*

Another participant reflected, *"It's new to me, I never come across playing Sitting LVB!"*

Playing LVB in a Wheelchair versus in a Sitting Position

Focus group interviews revealed that participants with higher mobility (lower level of disability) enjoyed playing LVB in the sitting position, whereas those with lower mobility (higher level of disability) felt more enjoyment while playing LVB in a wheelchair.

One participant said, *"I prefer playing in a sitting position because I can crawl freely on the floor."*

Another participant echoed, *"With my higher mobility, I like sitting on the floor. I can't manage to play and control my wheelchair concurrently. I feel free while playing on the floor."*

In addition to the sense of freedom, playing on the floor necessitated a larger amount of exercise and better judgment of the directions and positions of the ball.

Three participants reflected, *"Playing on the floor demands a greater amount of exercise, like running with our hands. … We could better judge the directions and positions of the coming ball in a sitting position. This enables us to have a better control of when and where to receive, set, and hit back the ball. … Relative to playing in a wheelchair, playing on the floor necessitates higher mobility and more exercise and hence strengthens our legs, lumbar, and even the whole body."*

A few participants with a weak lumbar region and higher level of disabilities enjoyed playing in a wheelchair.

One participant with serious disability reflected, *"I think it is a matter of mobility. Amputees and players with light polio can move better on the floor. However, for players with higher level of disabilities like me, we can play better in our wheelchairs. I am sure we can play and progress well."*

Another participant commented, *"I am good at controlling my wheelchair, even moving up and down staircases…. Given time and after mastering the techniques, I am pretty sure we can play well in our wheelchairs."*

Constraints and Potential Risks in Playing LVB

Body Constraints

Participants who could not sit self-supported on the floor enjoyed playing in wheelchairs as this gave them support and mobility. Some participants opined that their ability to play SLVB was subject to their body constraints.

One participant reflected, *"It really depends on your health status. Even with my relatively strong hands and lumbar, I don't know where and how to put my legs. It's really inconvenient. Owing to polio, I can't control the movement of my leg. It is difficult to move."*

Another participant who had spinal cord injury explained, *"My hands tremble when I receive a ball. Trembling starts when I stretch out my hands. I can't touch the ball."*

One participant said, *"I cannot sit properly. I can sit, but when I move, I will shake like a salmon."*

Safety Concerns

Safety is a concern when playing sports, particularly for people with relatively low fitness levels as their disability conditions posed a potential risk while playing SLVB.

One of the participants revealed, *"Sometimes, I was hit by the ball. Sometimes, I bumped into my teammates."*

When asked if their limbs and elbows were vulnerable to injury, some participants opined that potential risks could be reduced by wearing protective gear.

One participant said, *"We could protect our elbows from being hurt by wearing protective pads."*

Another participant echoed, *"We should also protect our degraded buttocks by wearing thicker trousers."*

Some participants opined that SLVB was comparatively safer than other wheelchair sports because it was non-impactful.

"Compared with traditional volleyball, which is heavier and harder, LVB does not hurt much even we hit it hard.…The chance of getting hurt is lower when compared with playing traditional volleyball where one is easy to hurt his/her fingers."

Suggestions for Fine-tuning Future LVB Intervention Programmes

Many participants suggested simpler rules, tailored according to the nature and levels of their disabilities, so that they could enjoy playing LVB either in a wheelchair or in a sitting position. One participant suggested that the ball should be allowed to bounce at least once in each pass.

Another participant echoed, *"To cater for players with lower activity level (e.g., players using electric wheelchairs), we had better allow the ball to bounce twice in each pass."*

Yet another participant commented on the rules of the game, *"We have different nature and levels of disabilities. It would be better if the net levels could be adjusted to cater proportionately for players sitting in wheelchairs and on the floor."*

One participant reflected, *"As beginners, it is too rush for us to allow merely three passes. We had better have four passes initially and then fall back to three passes once we are used to playing SLVB."*

Another participant opined, *"To make the best use of each team member's functional ability, we should allow free sitting positions up to the decision of the players while practising to serve by rotation."*

One of the participants suggested, *"To ensure level playing, formation of teams should be subject to the classification and point systems adopted for wheelchair basketball. In other words, each team should comprise a mix of players with comparable levels of disabilities defined by a ceiling point of the whole team (optional to have one able body)."*

Another participant, who agreed that having an able-bodied person as a team member would be beneficial, said, *"…having the coach play in the team will facilitate our learning and practising of the techniques."*

DISCUSSION

Participants' Perceptions about Playing LVB

Sports participants have a positive correlation with and a higher level of enjoyment than participants in other leisure activities (Hills & Argyle, 1998; Ruseski et al, 2014; Balish et al, 2016). LVB, being an interactive team game, requires players to move in different directions and react swiftly. Agility and dynamic balance are therefore crucial. Hedrick (2007) reveals that dynamic defensive and offensive movements occupy more than half of the total game time. It also means that cooperation in team is a must to organize the offense and defense in team. This is in line with the systematic review that team sport involvement was positively associated with improved teamwork, better mental health, including happiness (Eime et al, 2013). The current study's interview results were consistent with the aforementioned research results that participants deemed novelty, enjoyment, improved reactivity, and coordination, cooperation in team as positive outcomes.

Consistent with previous findings, the current study revealed that new activities were one of the elements, with respect to the attitude of people with physical disabilities, for an effective community-based PA intervention (Krops et al, 2018). Adopting a softer, lighter, and bigger ball and tailored rules for SLVB was a novelty to the participants. They were interested in finding out how it is played and whether they could manage to play SLVB.

Playing LVB in a Wheelchair versus in a Sitting Position

The results indicated that players with higher mobility (lower level of disability) enjoyed playing LVB in the sitting position, whereas those with lower mobility (higher level of disability) preferred playing LVB in their wheelchairs. Considering that players could be better able to judge the directions and hit the ball at different positions when sitting on the floor, and that they had higher mobility and got more exercise, playing LVB in a sitting position was preferred to playing in wheelchairs. This preference might refer to body autonomy - a wish to be able to control one's own life and act in harmony with one's self; however, Deci and Vansteenkiste (2004) indicated that this does not mean to be independent of others. Body autonomy is regarded as an obstacle to people with physical disability in their struggle for independence (Carolyn, 2001). Owing to obstacles such as transportation and the physical environment, they feel that they are unable to act for themselves and control their own bodies and lives (Carolyn, 2001). Conversely, some participants reflected positively that playing LVB in the sitting position helped them attain body autonomy and a sense of freedom.

Constraints and Potential Risks

Body Constraints

People without limbs or with deformity of limbs are considered to have a higher ability to play SLVB, because their spinal cords are healthy, than those with muscular dystrophy and spinal cord injury whose muscles and spinal cords do not provide self-support, which may affect their body balance and may cause further injuries when sitting on the floor (The Handicaps Welfare Association of Singapore, 2018).Similarly, the current study revealed that the ability of the participants to play SLVB was subject to their body constraints. Participants who could not sit on the floor independently preferred playing in wheelchairs, which provided them support and mobility. Future LVB intervention programmes may request participants capable of sitting unsupported on the floor to do so.

Safety Concern

Safety concern, often cited as a barrier for the people with disabilities participating in PA, should not discourage them from being active at a suitable level and intensity (Public Health England, 2018). Players with low fitness levels may hurt their elbows and buttocks if they do not play properly. Nevertheless, the potential risk of hurting themselves could be reduced with protective gear.

Suggestions for Fine-tuning Future LVB Intervention Programmes

Considering the different nature and levels of disabilities, many participants suggested adoption of simpler and tailored rules. Relaxed rules (e.g., lower net and allowing the ball to bounce once in each pass) at the initial stage enabled them to pick up the techniques of playing SLVB easily and allowed them to enjoy playing the game while seated either in a wheelchair or in a sitting position.

Limitations and Recommendations

To the best of the authors' knowledge, this is the first ever qualitative study to examine the perceptions among people with physical disabilities about playing LVB. The focus group interview was a simple and time-effective way of gaining a preliminary understanding of the participants' perceptions that novelty, happiness, improved reactivity, and coordination were positive outcomes. Interview results revealed that playing LVB in the sitting position was preferred to playing in wheelchairs.

However, limitations to this study exist. First, all the participants came from the same partner NGO, which might lead to groupthink. Generalisation, may therefore be limited. Second, compared with individual interviews, focus groups are not as efficient in covering the maximum depth on a specific issue. A particular disadvantage of a focus group is the possibility that the members may not be honest in expressing their personal opinions about the topic at hand. They may be hesitant in expressing their thoughts, particularly when their thoughts oppose the views of another participant.

Despite these limitations, the primary strength of this study is that it is the first to explore the suitability of playing SLVB among people with physical disabilities. The effectiveness of playing SLVB on health benefits among people with disabilities is a subject for future study. Furthermore, the content of this study is informative for developing future SLVB interventions and programmes for people with physical disability.

CONCLUSION

To reiterate, this qualitative study aimed at (a) understanding the perceptions of people with physical disability regarding playing Light Volleyball, (b) identifying the possible constraints and risks they might face while playing LVB, and (c) providing their suggestions for fine-tuning the intervention programmes.

In particular, this study gained a preliminary understanding of the perceptions and experiences of people with physical disabilities in the Light Volleyball trials for the refinement of the subsequent Sitting Light Volleyball intervention programmes.

When LVB is played among people with physical disabilities, the participants' body constraints and safety concerns must be considered, and the rules of the game must be tailored in accordance with the participants' body conditions and their skill levels at different stages of the intervention programme. Notably, the results of this study indicated that the effectiveness of playing SLVB on health benefits among people with physical disabilities needs further study. Also, SLVB can be one of the new physical activity options for future sport promotion among people with physical disabilities in the community.

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BRIEF REPORTS

Community-Based Rehabilitation in Nigeria: A Scoping Study of Literature

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ABSTRACT

Purpose: *Previous reviews of CBR literature provide scant evidence supporting community-based rehabilitation in Nigeria. This study aimed at discovering the extent of CBR impact in Nigeria by reviewing published literature and making it available to researchers, CBR project coordinators and managers, and policy-makers.*

Method: *A scoping study of CBR literature on people with disabilities, families and communities in Nigeria was conducted, using the databases of Pubmed, African Journal Online, Google Scholar, African Journal of Disability, Asksource.info and REHABDATA on naric.com, for articles published between the years 1990 – 2018. Fourteen studies met all the inclusion criteria and were classified according to type as descriptive (n = 4), theory (n = 5), impact (n = 2), and case studies (n = 2) or review (n = 1) papers.*

Results: *The results indicated a recent increase in community-based rehabilitation literature publication.*

Conclusion: *However, there is a need for more well-designed literature to better inform community-based rehabilitation practice.*

Key words: *community-based rehabilitation, disabilities, Nigeria, rehabilitation, persons with disabilities*

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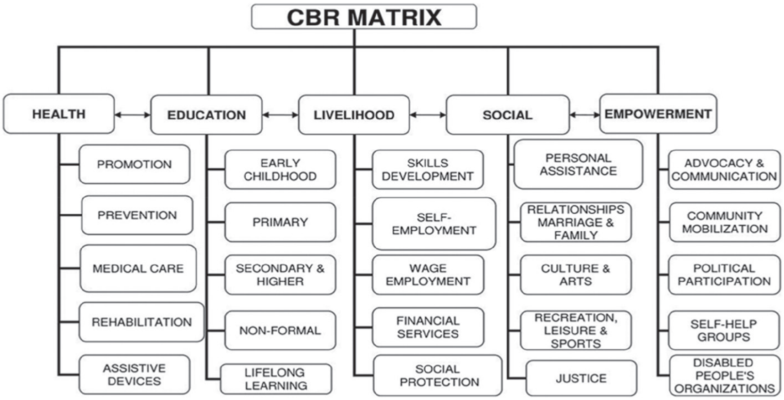
INTRODUCTION

About 15% of the world's population suffers from one form of disability or another (World Bank, 2011). According to Article 1 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, 2006), persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others. CBR has been presented as the most reliable approach for rehabilitation, empowerment and promotion of inclusion and participation of persons with disability since the eighties (WHO, 1981). It is a holistic strategy for rehabilitating persons with disabilities within the community, as against conventional rehabilitation programmes that are solely institutional or medical. It has been developed over the years and is now being operated in more than 100 developed and developing countries including Nigeria (Kuipers and Allen, 2004). In a joint position paper, the WHO, ILO and UNESCO (2005) defined CBR as "a strategy within general community development for the rehabilitation, equalisation of opportunities and social inclusion of all people with disabilities". The CBR strategies are defined in the form of a Matrix (see Figure 1).

Figure 1: CBR Matrix (obtained from the WHO)



The WHO's CBR strategy of coverage was formulated in the form of a Matrix consisting of 5 key components (health, education, livelihood, social and empowerment domains), each having 5 elements (presented in Figure 1). The components and elements of a CBR Matrix provide the basis of CBR programme objectives (WHO, 2010).

Previous studies on CBR literature (Mitchell, 1999; Wirz and Thomas, 2002; Finkenflugel et al, 2005) reported inadequate scientific research and evidence to inform its practice. Consequently, there was a positive response in developed countries that Cleaver and Nixon (2014) declared that CBR literature was plentiful, and advised future research to focus on systematic comparison of research production and dissemination.

However, there is a dearth of CBR literature in Nigeria, going by the fact that only 2 studies from Nigeria were identified and included in the recent scoping reviews of CBR literature, while there were 7 from South Africa (Cleaver and Nixon, 2014).

Objective

The purpose of this study was to identify and review relevant literature of CBR in Nigeria so that already published literature would be made available to researchers, CBR project coordinators and managers, and policy-makers.

METHOD

Study Design

The study utilised the scoping review outlined by Arskey and O'Malley (2005) and further developed by Levac et al (2010).

The search strategy was to identify relevant articles published between the years 1990 – 2018. The key words were 'Nigeria', 'community-based rehabilitation' and 'low- and middle-income countries', used in different combinations on the databases of Pubmed, African journal online, Google Scholar, African journal of disability, Asksource.info and REHABDATA on naric.com. Additionally, the references of the relevant studies were also searched to identify peer reviewed articles included in the study.

Inclusion Criteria

The publication had to be about:

- People with disabilities, families and communities in Nigeria;
- Self-described as pertaining to Community-Based Rehabilitation or with CBR mentioned in the title, abstract, keywords or body of the text; and
- The article had to be published between 1990 and 2018 (both years inclusive).

Analysis

As indicated in Figure 2 below, around 2900 articles were identified through the electronic databases and 1032 remained after removal of duplicates. About 950 articles were excluded after going through them and finding that they were not about CBR but more about rehabilitation exercises or techniques for a particular disease. Some articles had CBR in their title but were applicable to engineering. There remained 83 articles that were seemingly about CBR for people with disabilities and, following the rigorous application of the inclusion and exclusion criteria, 33 articles were downloaded for full text review. After further scrutiny of the full text, 19 studies were excluded for not fitting in totally with the inclusion criteria. Finally, 14 articles were selected for inclusion in this study (see Table 1).

Figure 2: Flow Chart for steps in Identification of Studies

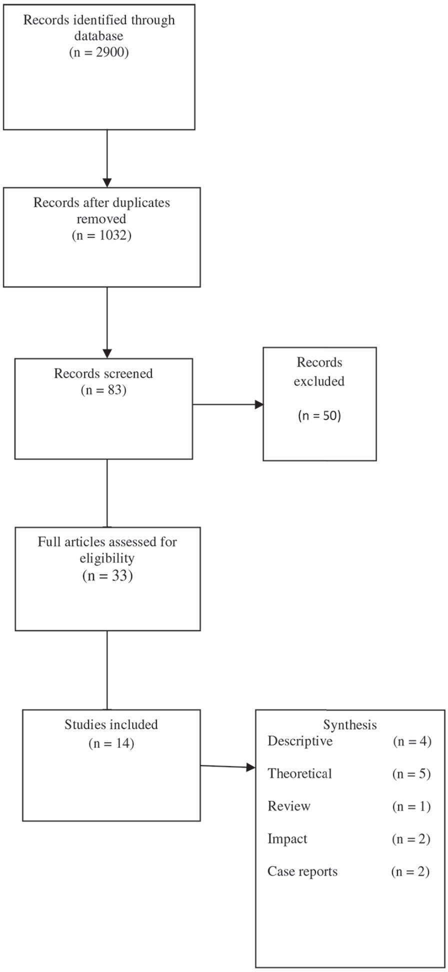


Table 1: List of Included Papers

Authors (Year)	Journals	Type of study	Empirical Research
Patrick and Oluseyi (2015)	International Journal of humanities, social sciences and education	Descriptive	Yes
Effiong and Ekpenyong (2017)	Journal of sociology, psychology and anthropology in practice	Impact	Yes
Alade (2004)	British Journal of special education	Case report	No
Igwesi-Chidobe and Udoka (2013)	International Journal of health sciences and research	Descriptive	Yes
Chakraborty et al. (2017)	BJPSYCH International	Case report	No
Asibi et al (2016)	International Journal of preventive and public health sciences	Impact	Yes
Hamza et al (2011)	Journal of the Nigeria society of physiotherapy	Theory	No
Adaka et al (2014)	International Journal of technology and inclusive education	Theory	No
Ebenso et al (2010)	Leprosy Review	Review	No
Vermeer et al (2015)	Disability, CBR and Inclusive Development journal	Descriptive	No
Olaogun et al (2009)	African Journal of physiotherapy and rehabilitation sciences	Theory	No
Vershima (2014)	National Journal of inclusive education	Theory	No
Jacob (2015)	European Scientific Journal	Theory	No
Vincent-Onabajo and Mohammed (2018)	African Journal of disability	Descriptive	Yes

Publication Period

All the 14 articles identified were published between 2004 and 2018, with about 21% (n = 3) published in 2015.

Empirical Research

Of the 14 articles included, 6 (43%) presented an empirical research. The remaining articles that reviewed unpublished secondary data using a sound methodology (Ebenso et al, 2010), or presented thorough and insightful narrative accounts without research methods (Alade, 2004) were regarded as unempirical research.

Journals in which the Articles appeared

All the included articles were published in different journals. About 79% were published in international journals, 2 were published in Nigerian national journals and 1 was in a foreign national journal.

Authors of the Articles

None of the authors seemed to have more than one publication. Majority (n=8) of the first authors are affiliated to Nigerian universities, four are affiliated to foreign universities and one each to a foreign hospital and an NGO. CBR is a multi-speciality field and different professionals are involved in its delivery and study. In this study, special education professionals contributed about 36% (n=5) of the papers, followed by physiotherapists with 4 papers.

RESULTS

Types of Studies

The reviewed articles were classified on the basis of study type as descriptive, theory, impact, and case study or review paper. Table 2 below shows the criteria for classifying the articles.

Table 2: Description of Types of Articles

Type of Paper	Description
Impact studies	Articles reporting on studies assessing the effect of a CBR intervention for a specific group. To be included, articles should enclose a description of the research design, the research methods and results.
Descriptive studies	Articles describing outcomes of interest of a selected population at a defined moment (without an intervention being carried out) are included here.
Case reports	Articles describing a particular CBR project or an approach to a specific problem in or aspects of a CBR project.
Review papers	Articles based on earlier published work that gives an overview of knowledge in a specific area.
Theory papers	Articles that aim to provide a theoretical base for CBR. Includes ethnographic and phenomenological work as well as discussion papers and articles presenting general information on CBR.

Adapted from Finkenflugel et al (2005) with modification

Theory Papers

Majority of the papers (n=5) are classified as theory papers on CBR. Hamza et al (2011) looked at the emergence of CBR as an opportunity for people with disability to get the best out of physiotherapy, as well as for the physiotherapists to prepare for their role in the CBR model that seeks to improve the quality of life of persons with disabilities and their families. The authors also called on the policy-makers to develop innovative ways to utilise physiotherapists in the community. Vershima (2014) discussed how CBR can promote inclusive education for persons with disability and highlighted how an international Non-governmental Organisation was able to achieve this in Nigeria.

The rest of the papers commented on the general principles of CBR regarding rehabilitation, participation and inclusion of people with disabilities (Olaogun et al, 2009; Adaka et al, 2014; Jacob, 2015).

Descriptive Papers

Four studies were classified as descriptive articles. All the studies used cross-sectional surveys and semi-structured questionnaires. Two of them used an outcome measure (Patrick and Oluseyi, 2015; Vincent-Onabajo and Mohammed,

2018) and one used a focus group discussion (Vermeer et al, 2015). The studies described a specific outcome of interest. Patrick and Oluseyi (2015) carried out a correlational survey on how rehabilitation depends on the quality of healthcare, service, personnel, material and financial resources. Vincent-Onabajo and Mohammed (2018) focused on the preference for rehabilitation settings among stroke survivors. Igwesi-Chidobe and Udoka (2013) studied the knowledge and attitude of physiotherapists towards CBR. Lastly, Vermeer et al (2015) described the role of traditional leadership of persons with disabilities on the success of a CBR programme.

Review Paper

Only one study (Ebenso et al, 2010) identified itself as a review study, and was also classified as such. The paper discussed the 13-year journey of the rehabilitation of persons with leprosy and its transformation from socioeconomic rehabilitation into a coordinated community-based rehabilitation. The study indicated that combining CBR principles and community development projects can stimulate improvements in well-being, self-esteem and reintegration of people affected by leprosy into the community.

Case Reports

The 2 studies classified as case reports described rehabilitation programmes that started as centre-based and later transformed into community-based so as to facilitate reintegration into the community and remove barriers and stigmatisation. The study by Chakraborty et al (2017) gave a narrative of a mental health rehabilitation programme that started as centre-based in Edawu community of Benue state through a partnership with a UK-based NGO and the Nigerian government, and later transformed into CBR.

The second study by Alade (2004) gave a narrative of a community-based vocational rehabilitation programme, an empowerment programme instituted by the International Labour Organisation (ILO) and the United Nations Development Programme (UNDP) that started in Oyo in partnership with the state government. The programme was later extended to 5 other States.

Impact Papers

Two studies fell into the category of impact studies. The studies determined the impact of CBR on beneficiaries of the CBR programme in 2 States - Plateau and

Akwa Ibom (Asibi et al, 2016; Effiong and Ekpenyong, 2017). The studies used both qualitative and quantitative methods to determine the effectiveness of the CBR intervention retrospectively.

Table 3: Some Evidence of the Impact of CBR in Nigeria

Authors (Year)	Intervention	Target Population	Evidence of Impact	Assessment
Effiong and Ekpenyong (2017)	Not specified	Persons with disability – random sample from all beneficiaries of CBR (n=436)	The findings revealed improvements in five elements of livelihood (skill development, self employment, wages employment, financial services and social protection).	Researcher interviewed beneficiaries using a 4- point Likert Scale structured questio-nnaire.
Asibi et al (2017)	Not specified (partly institution – based CBR programme)	Persons with visual impairment (n=16)	Beneficiaries became independent (n=12). Visually impaired persons acquired vocational skills (n=13). Many beneficiaries secured paid employment through the programme (n = 8). Facilitation of economic reintegration in the society (n=13). Improved mobility and orientation skills.	Researcher interviewed beneficiaries using structured questio-nnaire.
Alade (2004)	Community-based vocational training.	Persons with disability (n = 155) as part of community-based vocational rehabilitation pilot project in Oyo state, 1991.	90% of the beneficiaries were gainfully employed and thus facilitating inclusion into society.	Interviews with chairperson and coordinator of the project and review of record and reports of social workers.

DISCUSSION

The purpose of the current review was to identify relevant literature about CBR in Nigeria and review the work with the aim of making published literature available to researchers, CBR project coordinators and managers, and policy-makers.

Some of the CBR studies from Nigeria that were included in the previous CBR literature reviews were not included in this study as they did not fulfil the inclusion criteria. For instance, Finkenflugel et al (2005) considered a study by Hartley and Wirz (2002) on the development of a theoretical model to support people with communication disabilities using previous studies on CBR, although the authors themselves did not describe their study as a CBR article. Similarly, Velema et al (2008) also described a study on a socio-economic rehabilitation project by Ebenso et al (2007) as CBR, but Ebenso et al (2010) said that the aforementioned project was transformed into community-based rehabilitation, implying that initially it was not a CBR project. Furthermore, the study by Odebiyi et al (2008), which was cited by Cleaver and Nixon (2014) as CBR, was not about people with disability.

The articles were categorised as empirical research only in order to describe the empiricism of CBR literature in Nigeria and not to assess the quality of the published articles, as that is not the function of a scoping study (Arksey and O' Malley, 2005).

CONCLUSION

The findings of this study showed that there is a dearth of CBR literature in Nigeria, considering the fact that only 14 studies were found. The previous reviews of CBR (Finkenflugel et al, 2005; Velema et al, 2008; Cleaver and Nixon, 2014; Bowers et al, 2015) listed 17 studies from South Africa, while Nigeria had only 7 (assuming all were about CBR). This shows that Nigeria, with the highest number of persons with disabilities in Africa, has been lax in producing peer reviewed articles to better the lives of persons with disability. However, the publishing trend shows that there is a recent improvement in CBR literature publication, as about 64% (n = 9) of the articles were published in the last 5 years. The majority of the articles published were theory papers (n = 5), indicating a need for comprehensive intervention studies, case reports and descriptive studies to better inform practice. The findings show that there is no prominent person who can be called an authority on CBR in Nigeria. The authors are mostly academicians and, with a few exceptions, are probably not working directly with people with disabilities. There are a lot of on-going CBR programmes in Nigeria but no published studies on their modus operandi, impact or success stories.

Future studies should focus more on well-designed studies of CBR in Nigeria, on impact, implementation and the role of mid-level community rehabilitation facilitators. Also, with the passage of the Disability Bill in Nigeria, the government should create a Community-based Rehabilitation department in the Ministry of Social Welfare, as has been done in other African countries, to facilitate inclusion and participation of persons with disability.

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Stance Phase Kinematics in Ankle Joint during Ambulation on Uneven Surface: A Comparison between Stroke Survivors and Typical Adults

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ABSTRACT

Purpose: *Gait impairment is a common disability among stroke survivors and is a known risk factor of falls. Outdoor ambulation is essential for everyone, even for basic activities of daily living, but routine assessment of stroke survivors concentrates mainly on indoor ambulation and function. This study is an attempt to document gait parameters in stroke survivors and typical adults during outdoor ambulation.*

Method: *For this prospective pilot study, 7 chronic stroke survivors and 7 age-matched typical adults were recruited by convenience. Measurements were taken of their ankle and subtalar joint angles during various phases of gait, using video analysing software, Kinovea 0.8.15.*

Results: *Large differences in range of motion in the ankle and subtalar joints were noticed between stroke survivors and typical adults during ambulation on various surfaces. During ambulation on a firm surface, plantar flexion range of motion at the ankle was greater at initial contact and mid-stance, whereas on pebbled surfaces vast differences could be seen on initial contact and mid-stance.*

Conclusion and Implications: *Significant stance phase deviations are evident in stroke survivors during ambulation on uneven terrain. This may be a risk for falls and musculoskeletal degeneration. Although definitive conclusions cannot be drawn due to the small sample size, these findings indicate a need for considering outdoor gait evaluation in routine practice in the community. Mobility correlates highly with quality of life and meaningful strategies to adopt safe ambulation methods can be developed only with proper evaluation methods.*

Key words: *joint kinematics, uneven walking, gait alterations, uneven terrain, outdoor ambulation*

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INTRODUCTION

Locomotor impairment is a common disability in stroke survivors and is a known risk factor of fall (Jaffe et al, 2004). Navigation of uneven terrain is essential for residents of rural regions in much of the developing world, even for basic activities of daily living (BADL) as evidenced by anecdotal and observational accounts. Literature suggests that kinematic and kinetic variables are altered during uneven terrain ambulation; hence increased biomechanical adaptations are required. During outdoor ambulation, stroke survivors are exposed to additional risk factors of fall, due to compromised ability to step over objects and decreased endurance (Medifocus Guidebook On Stroke Rehabilitation, 2010). These factors can result in enforced confinement to the house which can negatively impact their quality of life (QOL).

The International Classification of Functioning, Disability, and Health (ICF) lists walking on different surfaces in the brief core set for stroke. This underpins the importance of outdoor ambulation.

Objective

Stance phase control and stability are essential for uneven surface ambulation. It is hypothesised that stroke survivors may have difficulty with distal joint stability and control. However, gait parameters during uneven surface ambulation have not been adequately described in literature. This study is an attempt to evaluate kinematic gait parameters of the ankle and foot in stroke survivors, in comparison to typical adults.

METHOD

Study Design

Methodological descriptions of this observational exploratory study followed the STROBE guidelines with an objective to compare kinematic gait characteristics between stroke survivors and typical adults during ambulation on level, pebbled and sandy surfaces.

Study Setting

The study setting was a simulated laboratory with a level walkway measuring 10 metres and a raised platform of pebbles and sand measuring 10×3 m, constructed to mimic the terrains commonly encountered in the rural plain areas (Figures 1 & 2). The terrain in hilly areas is difficult to simulate in a lab, hence was not attempted in this study.

Study Sample

The study incorporated the convenience sampling strategy and recruited 7 chronic adult stroke survivors and 7 age- and gender-matched typical adults.

Stroke survivors were recruited for the study if they fulfilled the following criteria:

- Able to walk independently without orthotics and with or without walking aids on the target surfaces (Functional ambulatory category 4 & 5);
- Utilising walking as the major mode of ambulation with functional ROM and muscle strength in the lower extremity;
- Without any other pathologies or comorbidities that might influence gait pattern, including sensory-perceptual problems that may impair safety as identified in clinical examination;
- Orthopaedic dysfunction, fractures, vascular complications in the lower limb, lower limb or abdominal surgeries, cognitive impairments that may affect the safety of the participants;
- Had the stroke more than two years previously (post-natural recovery phase of stroke) (Skilbeck et al, 1983);
- Spasticity of more than 1 on a modified Ashworth Scale in the lower extremity; and,
- Age above 18 years.

Since this is a preliminary exploratory study, the sample size for typical adults was limited to data saturation. Data saturation was considered as the number of clients recruited who showed unique characteristics. After that, participants were recruited in whom no unique characteristics were identified (Saunders et al, 2018). Typical participants without any condition that could potentially affect gait, including orthopaedic systemic illnesses and cardiopulmonary morbidities, were recruited to match the stroke survivors in age and gender. Thus, 7 typical adults and 7 chronic stroke survivors were recruited as per criteria.

The recruited participants were informed about the study and written informed consent was obtained.

Equipment and Study Protocol

The study was performed in the gait laboratory of the institution in the simulated setting described earlier.

Two logistics 720 HD web cameras mounted on tripods (Neilsen et al, 2008; Patricoski et al, 2009) were connected to two laptops (32 bit Toshiba). Camera 1 was placed at the end of the walking area and 55cm above the floor so as to cover anterior and posterior views (Baker, 2006). Camera 2 was placed at a distance of 3 m lateral to the mid-portion of the walking area and 55cm above the floor to cover the lateral view (Figure 1).

Figure 1: Illustration of Study Platform (even surface) and Technical Arrangements

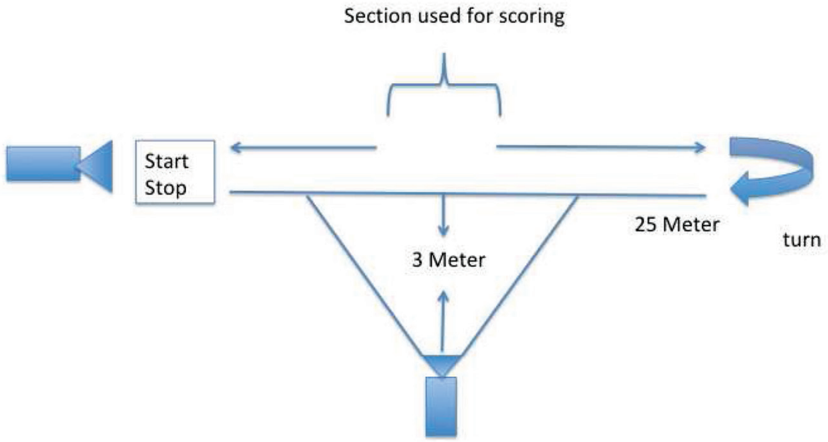
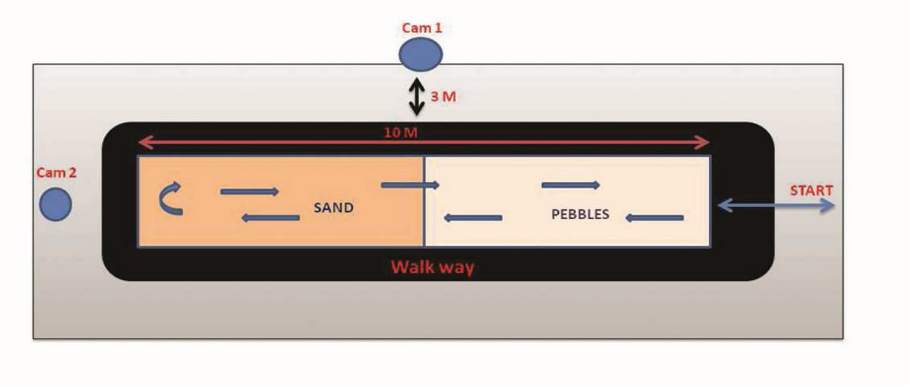


Figure 2: Illustration of Study Platform (uneven surface) and Technical Arrangements



To ensure the technical aspects of recording and adjustments, both laptops were operated by separate technicians. Greatest visualisation of the lower limb joints was ensured by fixing the optical axis of the camera in relation to the knee joint (Neilsen et al, 2008). The gait was captured at a frame rate of 30 fps (frames per second) and with a frame width of 1280×720 pixels.

Participant Preparation

Relevant bony landmarks were exposed and marked with fluorescent colour tape markers of 25mm (Neilsen et al, 2008). The bony landmarks are given in Table 1(Mathew J et al, 2017).

Table 1: List of Bony Landmarks identified

List of Bony Landmarks identified	
Segment	**Bony prominence**
Foot	-head of 1st metatarsal (dorsal) -head of 3rd metatarsal (dorsal -head of 5th metatarsal (lateral)
Ankle	-medial and lateral malleolus -calcaneal tuberosity -achilles tendon -lower 1/3rd of tibia (anterior)
Knee	-lateral condyle of femur -midpoint of patella
Hip and Pelvis	-greater trochanter -anterior superior iliac spine -posterior superior iliac spine -iliac tubercle
Upper limbs	-radial and ulnar styloid process -medial and lateral condyles of humerus - acromion process

Video Recording

Video recording was completed in two phases.

In Phase 1, stroke survivors were allowed to become accustomed to the walkway. Following this, they were instructed to walk barefoot for two laps at a self-selected speed on the walking areas (even, sand and pebbled platforms respectively). For safety, a physiotherapist accompanied the participant without making direct contact. Gait belts were secured as per protocol to allow for the therapist to stabilise the client if needed. Recording on both cameras was done simultaneously.

In phase 2, the same procedure was repeated with age- and gender-matched typical adults.

Video Analysis

Videos of typical participants were imported to Kinovea 0.8.15 version for analysis to draw normative values of range of motion (ROM) at the ankle and subtalar joints. Using different tools, the required points of the walking surfaces were marked on the software for better understanding (starting point, mid-portion, etc.). The initial and final 3 to 4 cycles of gait were not considered for analysis in order to control for initiation and fatigue. Thus, only the cycles covered in the middle 6m (3 to 4 cycles) were analysed. Joint kinematics was measured and recorded using different tools available in the software. Joint angles at the same event were taken from at least 3 consecutive cycles to increase the accuracy in measurement. Similarly, videos of stroke survivors were also analysed.

Data Analysis

Due to the small sample size and the outliers, non-parametric tests were computed. Mann- Whitney U test was used for comparison. Descriptive statistics were computed where comparison was not possible.

Ethics Approval

Approval from the institutional Ethical Committee of the affiliated Medical College was obtained (Reg No. 09_T046_95969).

RESULTS

The demographic characteristics of participants are depicted in Table 2.

Table 2: Demographic Profile of Participants (N=14)

		Typical Adult	**Person with Stroke**
Gender	Male	3	3
	Female	4	4
Side of stroke	Right		3
	Left		4
Range of motion of lower limb joints		Full	Functional for ambulation [8].

There was consistency of ROM among typical participants in ankle and subtalar range of motion during all phases of stance. The values on various surfaces are shown in Table 3.

Table 3: Kinematic Profile of Typical Adults during Stance Phase of Gait on Different Surfaces

Events	**Range of Motion(degrees) -Mean**					
	Ankle Joint			**Subtalar Joint**		
	Pebbles	**Sand**	**Firm**	**Pebbles**	**Sand**	**Firm**
IC	8.3°-10.3 PF	13.3° – 13.7DF	1.7-3.1° PF	12.3°– 14.6Ev	11° -12.7Ev	9.4-10.7°Ev
LR	12°- 13.3PF	11.3° – 12.6PF	7.2-9.3° PF	22.7°- 24Ev	12.3° – 11.7Ev	9.3-10.6°Ev
MS	8.6°- 9.7DF	5.3° – 6.7DF	4.3-5.4° DF	25.3°– 25.7Ev	15.6° – 16.3Ev	9.1-10.3°Ev
TS	10°-13DF	8.6° – 10DF	8.0-9.1° DF	12.7° – 13.6In	9.6° – 10.3In	8.6-9.3° In
PS	7.6°- 8.3PF	9° – 10PF	9.4-11.3° PF	13.6°– 15.7In	12.3° – 13In	8.0-9.2° In

(IC- initial contact; LR - loading response; MS - mid stance; TS - terminal stand; PS - pre swing; PF - plantar flexion; DF - Dorsiflexion; Ev - eversion; In - inversion)

The kinematic profile of stroke survivors is given in Table 4.

Table 4: Kinematic Profile of Stroke Survivors during Stance Phase of Gait on Different Surfaces

Events	Range of Motion(degrees) -Mean					
	Ankle Joint			**Subtalar Joint**		
	Pebbles	**Sand**	**Firm**	**Pebbles**	**Sand**	**Firm**
IC	5 PF-13.6 PF	12 PF-15PF	3.2-4.3 ° PF	16 Ev-18Ev	11 Ev-12.7 Ev	10.8 ° eV-12.3 ° eV
LR	6 DF-9.3 PF	10.6 PF-11.6 PF	6.8-7.4 ° PF	10 Ev-21Ev	11.7 Ev-12.6 Ev	11.2 ° Ev-12.6°Ev
MS	12.3 DF-7.6 PF	8 PF-10.3 PF	5.3-6.4 ° DF	21 Ev-23Ev	16.3 Ev-16.8Ev	15.9 ° Ev-12.8°Ev
TS	4 DF-6.3 PF	7.6 PF-12 PF	8.1-9.0 ° DF	10 Ev-12Ev	10.3 In-10.8 In	8.6 ° Ev-10.4°Ev
PS	3.3 PF-7.6 PF	12 PF-14 PF	9.6-11.0 ° PF	10 Ev-11 Ev	12.6 In-13 In	11.8 ° Ev-12.8°Ev

(IC - initial contact; LR - loading response; MS - mid stance; TS - terminal stand; PS - pre swing; PF - plantar flexion; DF - Dorsiflexion; Ev - eversion; In - inversion)

During analysis, one client showed a large deviation in ROM from the other six. Hence this person's data was excluded from analysis.

During loading response (LR), a large difference in kinematics at ankle joint between the stroke survivors (6°DF- 9.3°PF) and typical adults (12 °- 13.3PF) was noticed during gait on pebbles. During ambulation on sand, the kinematic profile of the stroke survivors was different from typical adults in all the events of stance at the ankle joint. Subtalar ROM was considerably reduced in stroke survivors on both sand and pebbles in comparison to typical adults.

Ankle Joint

Due to the difference in the direction of movement (plantar flexion and dorsiflexion) between the two groups, only those phases of gait on similar surfaces (sand and pebble) where the movement was in the same direction for both groups were analysed using non-parametric test of comparison (Mann-Whitney U test). Results are summarised in Table 5.

Table 5: Comparison of Plantar Flexion Range of Motion between Typical Adults and Persons with Stroke during Ambulation on Firm Surfaces

	Participants	**Phases of Stance**				
		IC	**LR**	**MS**	**TS**	**PS**
ROM degrees (Mean ± SD)	**Typical Adults**	2.14±0.9	7.57±1.27	4.93 ±0.42	8.63 ±0.58	10.16 ±1.02
	Persons with Stroke	3.43 ±0.9	6.71 ±1.1	5.97 ±0.38	8.53 ±0.39	9.87 ±.0.55
Diff.(95% CI)		1.29, [0.241, 2.338]	0.86,[-0.523, 2.243]	1.04, [0.573, 1.506]	0.1,[-0.475, 0.675]	0.29,[-0.664, 1.244]
Z		-2.14	-1.25	-2.95	-.13	-0.6
P		0.32	0.21	0.003	0.89	0.6

(ROM - Range of motion; IC - initial contact; LR - loading response; MS - mid stance; TS - terminal stand; PS - pre swing; PF - plantar flexion; DF – Dorsiflexion; Ev – eversion; In – inversion; SD - Standard deviation)

On firm surfaces, both groups (typical adults and stroke survivors) showed a similar direction of movement (plantar flexion). During initial contact (IC) and mid-stance (MS), plantar flexion was greater in stroke survivors than typical adults with greater differences noted in MS. But in loading response (LR), terminal stance (TS) and pre-swing (PS) plantar flexion was greater in typical adults than the stroke clients.

Table 6: Differences in Plantar Flexion Range of Motion between Typical Adults and Persons with Stroke during Ambulation on Pebbled and Sand Surfaces

	Participants	**Phases of Stance (Pebble)**		**Phases of Stance (Sand)**	
		IC	**MS**	**IC**	**MS**
ROM degrees (Mean ± SD)	**Typical Adults**	9.14±1.5	8.80±1.07	13.57±1.12	11.43±1.40
	Persons with Stroke	9.29±0.76	11.57±1.27	13.57±.98	10.71±0.76

Diff. (95% CI)		0.15,[-1.234, 1.534]	2.77,[1.402, 4.137]	0,[-1.225, 1.225]	0.72,[-0.591, 2.031]
Z		-3.176	-3.04	-.137	-1.008
P		0.001	0.002	0.89	0.313

(ROM - Range of motion; IC - initial contact; MS - mid stance; SD - Standard deviation)

During ambulation on pebbled surfaces (Table 6), there was an increase in plantar flexion range of motion in stroke survivors in both IC and MS. Other phases of gait could not be compared as the direction of movement was opposite to each other in the two groups.

During ambulation on sand (Table 6), no statistically significant difference (p value=0.89) was noted between groups at IC but plantar flexion in typical adults was greater than the stroke group during LR.

Subtalar Joint

Table 7: Differences in Subtalar Joint Range of Motion between Typical Adults and Persons with Stroke during Ambulation on Firm Surfaces

	Participants	**Phases of Stance**				
		IC	**LR**	**MS**	**TS**	**PS**
ROM degrees (Mean ± SD)	**Typical Adults**	10.23±.587	9.90±0.56	9.78±0.5	8.93.26	8.93±0.8
	Persons with Stroke	11.51±1.02	11.91±0.54	13.66±2.22	9.44±0.78	12.30±0.33
Diff. (95% CI)		1.28,[0.310, 2.249].	2.01,[1.369, 2.650]	3.88,[2.006, 5.754]	0.51,[-0.167, 1.187]	3.37,[2.657, 4.0827]
Z		-2.18	-3.13	-3.13	-1.54	-3.14
P		0.029	0.002	0.002	0.245	0.002

(ROM - Range of motion; IC - initial contact; LR - loading response; MS - mid stance,
TS - terminal stand; PS - pre swing; PF - plantar flexion; DF - Dorsiflexion; Ev - eversion;
In - inversion; SD - Standard deviation)

During ambulation on firm surfaces (Table 7), the subtalar joint showed a significantly greater range of motion in persons with stroke during all the phases of stance. The direction of movement was similar in both groups during all phases of gait; hence comparison was possible in all phases of gait. MS and PS phases showed maximum difference between groups in subtalar range of motion.

Table 8: Differences in Subtalar Joint Range of Motion between Typical Adults and Persons with Stroke during Ambulation on Pebbled Surfaces

	Participants	**Phases of Stance**				
		IC	**LR**	**MS**	**TS**	**PS**
ROM degrees (Mean ± SD)	**Typical Adults**	13.34±0.83	23.41±0.84	25.60±0.36	12.98±0.53	14.41±0.82
	Persons with Stroke	16.78±0.92	14.67±3.16	22.26±0.84	26.64±41.18	10.70±0.60
Diff. (95% CI)		3.44,[2.419, 4.460]	8.74,[6.047, 11.432]	3.34,[2.587, 4.092]	13.66,[-20.255, 47.575]	3.71,[2.873, 4.546]
Z		-3.134	-3.130	-3.137	-2.049	-3.130
P		0.002	0.002	0.002	0.40	0.002

(ROM - Range of motion; IC - initial contact; LR - loading response; MS - mid stance;
TS - terminal stand; PS - pre swing; PF - plantar flexion; DF - Dorsiflexion; Ev - eversion;
In - inversion; SD - Standard deviation)

The direction of the movement of the subtalar joint during ambulation on the pebbled surface was similar between groups in all the phases of gait (Table 8). There was a large difference noted in the subtalar range of motion between groups in LR and TS.

Table 9: Differences in Subtalar Joint Range of Motion between Typical Adults and Persons with Stroke during Ambulation on Sand

	ROM in Mean +/- SD				
	IC	**LR**	**MS**	**TS**	**PS**
Typical Adults	11.92±0.71	11.59±0.46	16.0±0.29	10.14±0.44	12.71±0.35

Persons with Stroke	12.0±0.66	16.54±0.20	10.57±0.24	12.61±0.35	10.87±4.35
Diff. (95% CI)	1.84,[-1.753, 5.433]	4.95, [4.536, 5.363]	5.43, [5.12, 5.74]	2.47,[2.007, 2.933]	1.84, [-1.753, 5.433]
Z	-1.38	-3.14	-3.14	-3.14	-1.42
P	0.701	0.002	0.002	0.002	0.155

(ROM - Range of motion; IC - initial contact; LR - loading response; MS - mid stance; TS - terminal stand; PS - pre swing; PF - plantar flexion; DF - Dorsiflexion; Ev - eversion; In -inversion; SD - Standard deviation)

During ambulation on sand, the subtalar range of motion was greater in the typical adult group than the stroke group during MS and PS. The subtalar range of motion was greater in the stroke sample than the typical adult sample at IC, LR and TS (Table 9).

DISCUSSION

The researchers examined the differences in kinematic variables of ankle and subtalar joint during gait performance as the distal joints are crucial in gait stability. This study was conceived as a large observational study. However, the appearance of large potentially risky deviations in all participants compelled the curtailment of the study for ethical reasons. Hence this is presented as a preliminary explorative study. No research-related injury was reported during the study.

This study demonstrates that stroke survivors show vast deviations from typical adults in distal joint ROM. These results are consistent with existing literature that stroke survivors have limited ROM in primary joints, and compensatory movements may increase ROM in secondary joints. Reduced or altered ROM at the primary joints can be explained on the basis of excessive overactivity of ankle plantar flexors (Cappozzo et al, 2005; Yavuzer, 2006; Tranberg, 2010; Bensmail et al, 2013; Kim et al, 2016).

Typical adults show bilaterally symmetrical kinematic characteristics. Stroke survivors show similar ROM to typical adults on the unaffected side. The compensatory mechanisms seen in the affected side during the gait are a reversal of dorsiflexion and plantar flexion. This finding was unexpected and can be explained partially by the patterns adopted by clients. The primary intention of gait evaluation and analysis is to provide early intervention to improve the performance of clients. This study suggests that gait evaluation on uneven surfaces normally negotiated by the client must form a part of routine evaluation. Increased plantar flexion during swing resulting in foot drag is routinely considered during rehabilitation. Stance phase abnormalities are less often considered. Hence this paper focused on stance phase alterations only.

During ambulation on pebbled surfaces, plantar flexion was greater in stroke clients than in typical adults during initial contact and mid-stance. The reasons may be the greater reliance on gravity and inadequate co-contraction of the ankle musculature. This is a potential cause of ankle instability and recurrent minor trauma (Paolucci et al, 2008).

During ambulation on sand, IC and LR showed a similar direction of movement, with no significant difference between groups. The values are similar for both groups in this cohort. This could be due to the small size of the sample and the inclusion criteria adopted. Post hoc power analysis revealed a power of 0.4. This is a limitation of this study and further studies must consider this aspect. The confidence interval in many cases was wide which indicates that gait characteristics in stroke survivors are not similar, which can also be attributed to the small sample size. The direction of movement itself being altered in stroke survivors at the ankle joint is another notable finding. Due to this, factor comparisons were not made in ankle ROM during ambulation on sand and pebbles in various phases of gait. These factors further underpin the importance of outdoor gait evaluation as a potential tool for fall risk.

Limitations

It is not possible to extract a definitive conclusion due to the smaller sample size. Hence this study is an initial exploratory study in this field. Further studies with a larger sample size are recommended.

CONCLUSION

This is an exploratory study of seven individuals and no definitive conclusions can be drawn. However, the findings of this study are important as the deviations were remarkable and identify major fall risk, thereby having an impact on the quality of life of stroke survivors. Analysis of gait on uneven surface ambulation must be taken up as a large-scale study, given the burden of stroke survivors in India. The impact of gait deviations on joint kinetics is a future direction that will inform rehabilitation professionals on strategies to prevent joint loading leading to dysfunction. Early intervention strategies to improve joint kinematics on different surfaces can potentially reduce the risk of falls, making the client safe to ambulate on uneven terrains.

Routine assessment of stroke survivors concentrates mainly on indoor ambulation and function. When they return to the community, their activities and participation are often restricted. One factor may be difficulty in mobility. Mobility correlates highly with quality of life. The results of this study imply that gait deviations during ambulation on uneven surfaces are significant and must form a routine part of the assessment of stroke survivors. Meaningful strategies to adopt safe ambulation methods can be developed only with proper evaluation methods. This study shows a wide variation in ankle and foot strategies adopted by stroke survivors. This further underscores the importance of doing uneven level gait analysis. Since this is a clinical study without the use of instrumented gait analysis, further analysis using instrumentation is warranted in future research in order to develop a clinical assessment tool for evaluation of gait on outdoor surfaces.

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LETTER TO EDITOR

Dear Editor,

Community Physiotherapy in India: Status Quo?

Community health services in India have played a major role in the prevention and treatment of chronic health conditions like cystic fibrosis (Byrne and Hardy, 2005), stroke (Young, 1994), and knee arthritis (Hay et al, 2006), among others. Community physiotherapy, an important component of community health services, is an underrated and less "attractive" profession (Rajan, 2012, 2013, 2015a, 2015b, 2017). When I was as an undergraduate physiotherapy student in 2002, in India, community physiotherapy was not considered a lucrative profession. Nevertheless, I felt drawn to this area of specialisation and have been working as a community physiotherapy clinician and researcher ever since graduation.

In the year 2015, I had the privilege of being invited to speak at an international conference in Gujarat, India. An opportunity arose to interact with the postgraduate physiotherapy students in an institution there. A questionnaire survey study was conducted to understand the motivations behind their choice of specialisation. Twenty-one female physiotherapists agreed to participate in the study. Their average age was 23.76 ±1.09 years, and thirteen of them were in their final (second) year of study. Only seven students had taken up physiotherapy studies as their first choice, while the remaining were either interested in other areas of specialisation such as medicine and dentistry (n=11) or were not aware of the profession (n=3). There were only four physiotherapists whose postgraduate specialisation was in community physiotherapy. Upon further enquiry, it emerged that community physiotherapy was perceived as a profession that has *"limited awareness among the general population"* (P5) and *"has no value in India"* (P6). Despite these perceptions, this area of specialisation was considered as *"the best profession to serve people"* (P3), and with *"great scope in the community, both as a preventive as well as curative service"* (P4). Although a small cohort, the findings from this study reiterate the lack of awareness and interest among physiotherapists in India to pursue this specialisation.

Over these many years, the field of community physiotherapy has not gained much importance and attention in India (Johnsey et al, 2013; Rajan, 2013, 2015a, 2015b, 2017). Community physiotherapy has immense potential to prevent and treat public health conditions. Improving the awareness and interest of physiotherapists and the general population (Johnsey et al, 2013; Sinha and Sharma, 2019) in this area of specialisation is the key to the success of community physiotherapy.

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

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

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