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RESEARCH PAPER

Disability and access to health care – a community based descriptive study

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Abstract

Purpose: The World Disability Report highlighted the need for adequate access to health and medical rehabilitation services for those with disability. Participants in a large community based survey in a low-income area were asked questions relating to their use of health related services. **Method:** Using random, cluster sampling a representative sample of 1083 households in a deprived area of Cape Town were approached and 152 people with disability were interviewed. **Results:** Those with disability were more likely to be male ($\chi^2 = 4.24, p = 0.03$) and unemployed ($\chi^2 = 66.89, p > 0.001$) compared to those without disability. The percentages reporting unmet needs were respectively: 54% for home-based care; 34.5% for assistive devices, 28.9% for medical rehabilitation services; and 2.5% for health services. Those over 65 years of age were less likely to have had the medical rehabilitation that they required ($\chi^2 = 8.00, p = 0.018$). There were fewer respondents with sensory and language disorders but these groups reported proportionately more unmet needs. The main problems with accessing services included inadequate finances (71%) and transport problems (72%). **Conclusion:** It is recommended that all efforts be expended to extend appropriate rehabilitation services, including home based-care and appliances to those identified as having disability, particularly to those older than 65 years. In addition, the services need to be affordable and accessible in terms of suitable transport, particularly in the light of the high unemployment rate and the large number of respondents with mobility problems.

Keywords

Access, disability, health care

History

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► Implications for Rehabilitation

- People with disability may be the most in need of additional health related care and the least able to access it.
- Transport and financial considerations were found to limit the ability to access appropriate care.
- Rehabilitation and health services need to reach out through home-based care and appropriate forms of rehabilitation delivery to ensure that those who are most in need of care, such as the elderly and those with more neglected forms of disability, are provided with the services that they require.

Introduction

The conceptual framework of the International Classification of Functioning Disability and Health recognises the impact of the environment on the ability of person with disabilities to meaningfully participate in the life of the community and to benefit from all services provided, including health and rehabilitation services [1]. The World Disability Report (the Report) recognises that people with disability need to be able to access appropriate mainstream health care and rehabilitation to a greater extent than people without disability [2]. Several reasons are suggested for

this, including those related to their health condition, such as secondary or co-morbid conditions, and greater vulnerability to violence, unintended injury and age related conditions. In high-income countries, those with disability account for a disproportionate amount of health care expenditure. In the US, for example, De Jong et al. analyzed the 1996 Medical Expenditure Panel Survey (MEPS) and concluded that individuals with disabilities use more health care services than do other. They reported that adults with functional problems accounted for one third of physician visits, 62% of hospital days, and 46% of adult-related health care expenditures [3]. Ironically, in many contexts, those who are most in need might be the least able to access appropriate health care, precisely due to the nature of their disability. The Report indicates that the percentage of people with disability unable to access required care is higher than for those without disability in every age range, and higher in low income compared

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to high-income countries [2]. Mobility limitations, compounded by the lack of adequate transport facilities might make access to health care exceedingly difficult. The obvious barriers to access include architectural barriers, and appropriate enabling equipment, such as lift or transferring devices, accessible scales, examination tables and mammography machines [4] are often not available. Attitudes of health professionals have also been identified as a barrier to accessing health services [5].

In addition, the prevalence of the major categories of ill-health and disability is greater among lower than higher socio-economic groups as demonstrated by Ataguba et al. [6]. They state “South Africa represents a classic example of the inverse care law; the lowest socio-economic groups bear the largest burden of ill-health but have the lowest level of health service utilisation and derive the least benefits from service use” [6].

The aim of this article was to respond to the recommendations made in the Report, specifically those pertaining to the need to gather data on rehabilitation needs, and unmet needs, disaggregated by sex, age and associated health condition [2]. This entailed an examination of the factors that impact on the ability of people with disability to access health care in a middle income country, among those who have the least amount of financial resources. It was hypothesised that a combination of functional limitations and environmental factors would have the greatest impact on access to services.

Method

Study design

The study was nested within a larger survey on the prevalence and epidemiology of disability. A descriptive cross-sectional household survey was conducted in an urban area in the Cape Town Metropolitan area, which has one of the lowest scores in the national Multiple Deprivation Index Survey [7] indicating extreme deprivation. The inhabitants are mostly isiXhosa speaking black Africans.

Sample

The sample size was calculated using Epi-Info StatCalc, Version 6. In a population of 100 000, with an estimated prevalence of disability of 5.2% [8], (95% Confidence Intervals 4.6–6.0%), the sample required was 2874 subjects. However, as cluster sampling was used at the level of geographical area, a design effect of 1.3 was used to allow for the similarities within each cluster. The final sample size required was therefore 3640. Anticipating that the average household consists of four members, the required number of households to be visited was a minimum of 910.

The proportion of free standing, semi-detached homes, flats and informal settlements was determined using census data relating to the suburb. Google Maps were used to identify the sampling frame and ensure that those in back yard, formal and informal housing were proportionally represented.

Using the aerial map of the area of the area, 14 informal settlement areas, 21 formal housing areas and one formal housing area in which back-yard dwellings were included were identified and demarcated giving a total of 36 discrete geographical areas. Each was then given a number and stratified random sampling was performed using the Excel random number function to select 23 small geographical areas, such as street blocks. Within each of these smaller areas, one of the four “corners” of the cluster or block was chosen randomly and ten dwellings in each street were identified on the map, starting from the second house to the left of the street corner and then including every second house from this point on until 10 houses were visited.

Randomised, stratified, cluster sampling was therefore utilized. If for any reason, respondents in the identified household could not be interviewed a further visit on an alternative time was attempted before exclusion. Subjects included all adults and children who were permanent residents in the household identified. The most senior member present at the time of the visit or the head of the household was asked to provide information on all the other members.

Instrumentation

The Washington Group on Disability Statistics Short Set of Questions [9] was used to identify people with disability. A demographic questionnaire was designed for the purpose of this study. It consisted of three sections concerned with demographic characteristics (e.g. age, education) social characteristics (e.g. household composition) and biomedical characteristics (e.g. duration of impairment, acute or chronic concomitant illness).

Questions which related to service delivery included whether the participants were aware of the different services, whether they needed the services and whether they had received the services. There was also a general question relating to problems with accessing services. The questionnaire was translated into isiXhosa and was piloted on a group of isiXhosa speaking people.

Procedure

Ten enumerators were recruited and trained on how to conduct the interview, and how to complete the questionnaire. A supervisor was employed to manage the data collection process and to ensure the accuracy of the data collected. The informant was interviewed and completed the demographic questions and the screening questionnaire for the whole sample. If he/she reported that there was a member of the household with a disability, this person was either immediately interviewed or an appointment was made to return to the household. Disability was defined according to Washington Group on Disability Statistics Screening Questions as those reporting “A lot of difficulty” in at least one domain. The people with disabilities then filled in the questionnaire which related to nature of their disability and their access to services. Proxy report was used when the person with disability was unable to respond to the questions, either because of age or nature of the disability.

Data management and analysis

Descriptive statistics were used to present the various components of disability. As medical rehabilitation is the focus of this article, this was chosen as the variable to discriminate between those able to access care and those in need who had not had intervention. Three groups were identified, those not needing rehabilitation (Not needed), those who needed and received rehabilitation (Received) and those who needed but had not received rehabilitation (Not received). Chi-squared was used to test for association between categorical variables such as gender and disability status or access to medical rehabilitation.

Ethical considerations

Ethical approval for the study was given by the Human Research Ethics Committee of the University of Cape Town and informed consent was obtained from all participants. In the case of minors or disabled person who were not able to give legal consent, written informed consent was obtained from the parent(s)/legal guardian. People identified as being in need of rehabilitation were informed about the relevant services in the area.

Table 1. Number of respondents reporting difficulty on the different Washington Group Screening Items ($n = 151$).

	No difficulty	Some difficulty	A lot	Cannot do at all	Total
Seeing	91	43	14	3	151
%	60.3	28.5	9.3	2.0	100.0
Hearing	85	35	28	3	151
%	56.3	23.2	18.5	2.0	100.0
Walking	23	11	78	39	151
%	15.2	7.3	51.7	25.8	100.0
Remembering	37	55	43	16	151
%	24.5	36.4	28.5	10.6	100.0
Self-care	79	30	25	17	151
%	52.3	19.9	16.6	11.3	100.0
Communication	97	23	19	12	151
%	64.2	15.2	12.6	7.9	100.0

Results

A total of 1083 households were approached. There were 44 refusals and data were gathered from 1039 informants relating to 3464 family members. There were 179 (5.2%) people who were reported to have a lot of problems in or unable to do in response to one of the screening questions. Of these 151 people with disability were available for interview. The responses of these 151 form the primary data for this paper. The mean age was 46.5 years ($SD = 20.5$, range 4–87, 29 missing responses) which was significantly older than the community sample (29.4 years, $SD = 16.6$; $t = 12.2$, $p < 0.001$). The underlying causes of the disability were post-coded as being unintentional injury (31.1%), aging and chronic diseases of life style (27.8%), childhood infections and birth trauma (17.9%), infection (8.0%) and other causes/missing (15.2%).

Of those with disability, 45.5% were female, compared to 54.22% of the sample ($\chi^2 = 4.24$, $p = 0.039$), the majority were unemployed (89.7% of those between 18 and 65) compared to 49.5% of the sample ($\chi^2 = 66.89$, $p > 0.001$) and 75.5% were receiving some form of grant.

The majority of respondents reported problems in the area of Mobility (85%) with 77% reporting a lot of difficulties or cannot do at all in this area (Table 1). The next most common problem was remembering (75%) with 39% reporting a lot of difficulties or cannot do.

Access to services

Of those who reported being in need of services, the largest percentage reporting that these needs were not met were in the areas of medical rehabilitation (30%), assistive devices (34.5%) and home-based care (56.4%). In contrast, only 2.5% reported being in need of medical care and not having received it (Table 2).

The specific services that were most required (both met and unmet) included physiotherapy, medication, home based care and the provision of wheelchairs and improved transport (Table 3).

There was no difference in the proportion of males and females who had had access to medical rehabilitation ($\chi^2 = 3.669$, $Df = 2$, $p = 0.160$). Similarly, there was no difference in the mean ranking of income categories, ($Z = 0.584$, $Df = 2$, $p = 0.558$), although those Not receiving had the lowest mean rank. Age did make a difference to access and the elderly (over 65 years of age) were less able to access treatment, with more than 50% of those needing not having received treatment ($\chi^2 8.00$, $df = 2$, $p = 0.081$; Table 4). People who reported hearing problems had the largest proportion of respondents who had needed but not received rehabilitation (52%). Those who had a disability secondary to infection were the least likely to have received needed

Table 2. Number of people with disability reporting services required and obtained ($n = 151$).

	Aware		Needed		Received		% Needing that did not receive
	Count	%	Count	%	Count	%	
Home Based Care							56.4
Yes	117	77.5	55	36.4	24	15.9	
No	31	20.5	83	55.0	113	74.8	
Missing	3	2.0	13	8.6	14	9.3	
Assistive devices							34.5
Yes	117	77.5	110	72.8	72	47.7	
No	27	17.9	30	19.9	70	46.4	
Missing	7	4.6	11	7.3	9	6.0	
Medical Rehabilitation							28.9
Yes	115	76.2	114	75.6	81	53.6	
No	30	19.9	26	17.2	68	45.0	
Missing	6	4.0	11	7.3	2	1.3	
Disability Counselling							17.6
Yes	118	78.1	108	71.5	89	58.9	
No	25	16.6	30	19.9	56	37.1	
Missing	8	5.3	13	8.6	6	4.0	
Welfare Services							12.2
Yes	134	88.7	123	81.5	108	71.5	
No	5	3.3	16	10.6	37	24.5	
Missing	12	7.9	12	7.9	6	4.0	
Health Services							2.5
Yes	120	79.5	122	80.8	119	78.8	
No	18	11.9	17	11.3	30	19.9	
Missing	13	8.6	12	7.9	2	1.3	

Table 3. Specific services required (met and unmet needs; $n = 121$, 30 missing, multiple responses).

	Count	Percent
Physiotherapy	25	16.6
Medication	22	12.6
Home based care	17	11.3
Wheelchair	13	6.0
Transport	13	5.3
Special school	10	6.0
Job placement	7	2.6
Walking aid	6	2.6
Spectacles	6	2.6
Disability grant	6	2.0
Hearing aid	4	2.6
Surgery	3	2.0
Prosthesis	2	1.3
Home for the elderly	2	1.3
Sports group	2	1.3
Occupational Therapy	1	0.7
HIV support group	1	0.7
Toilet	1	0.7
Computer	1	0.7
Support group for rape victims	1	0.7
Better access to health services – no queues	1	0.7
Missing	30	19.9

rehabilitation (42%) followed by those who had a chronic disease of life style (38%). Satisfaction with transport did not emerge as being associated with accessing needed rehabilitation services.

Problems with accessing services

Most of the respondents reported that they were unable to pay for services (70.9%) and that services were too far and they had no transport (72.2%). Other reasons for not accessing services were that they were not helping any longer (37.1%) that the respondents had reached the level of functioning that they had set

Table 4. Characteristics of those who did not need rehabilitation, those who needed it and received care and those who needed services but did not receive them.

	Not needed	Received	Not received	Total	% Needing that did not receive	Chi-sq (p)
Youth and adults	24	68	31	123		8.00 (0.018)
%	19.5	55.3	25.2		31.3	
Elderly (Over 65 years)	2	11	14	27		56.0
%	7.41	40.74	51.85		56.0	
Missing				2		
Functional limitation (multiple responses)						
Seeing	3	8	6	17		42.9
%	17.6	47.1	35.3		42.9	
Hearing	4	13	14	31		51.9
%	12.9	41.9	45.2		51.9	
Walking	16	67	34	117		33.7
%	13.7	57.3	29.1		33.7	
Remembering	9	34	16	59		32.0
%	15.3	57.6	27.1		32.0	
Self care	7	21	14	42		40.0
%	16.7	50.0	33.3		40.0	
Communication	4	15	12	31		44.4
%	12.90	48.39	38.71		44.4	
Underlying cause (most common)						
Infectious	0	7	5	12		41.7
%	0.0	58.3	41.7		41.7	
Maternal and child	8	14	5	27		26.3
%	29.6	51.9	18.5		26.3	
Chronic diseases of lifestyle	8	21	13	42		38.2
%	19.0	50.0	31.0		38.2	
Unintentional Injury	9	27	11	47		28.9
%	19.1	57.4	23.4		28.9	
Other				33		
Total						
Satisfaction with transport						
Satisfied	13	63	33	109		34.4
%	11.9	57.8	30.3		34.4	
Dissatisfied	6	13	11	30		45.8
%	20.0	43.3	36.7		45.8	
Missing				12		

as the goal of intervention and that services were no longer available (47.7%). Communication or a language barrier was reported as a problem with accessing services by 48.3% and 67.5% said that they were not satisfied with services. “Other” problems, reported by one or two respondents included poor staff attitudes and disrespect and the long waiting time for attention.

Discussion and conclusions

People with disabilities appear to have difficulty accessing medical rehabilitation and home care services. The sample is likely to be representative of those who dwell in deprived urban areas as the prevalence in this study was 5.2% which is equal to the 2011 census data and the 2011 General Household Survey [8] which reported that the highest prevalence occurs amongst the Black Africans, who generally reside in under-resourced communities. Not all of those identified as having a disability were interviewed but the questionnaire was filled in by 85% of PLWDs, which is a reasonable response rate.

There is a large unmet need for rehabilitation services and assistive devices, in that approximately one third of the respondents reported that they needed services but that they had not accessed them. This was in contrast to general health services which been consulted by all but 2.5%, a surprisingly high number as it has been noted that people with chronic illnesses and

disability often do not access health systems adequately [10]. The reason for this discrepancy may be that there are a large number of community health clinics in the area under study, as the Health Care 2010 strategy of the Western Cape, has focussed primarily on curative and preventative strategies [11]. However, few of them have rehabilitation personnel and those with disabilities might have found it difficult to attend clinics if they were not in the near vicinity, as borne out by the large number citing financial and transport difficulties. There is a system of designated transport for those with disabilities in the Cape Metro (Dial-a-Ride), but again, the participants did not seem to access the existing service.

A worrying finding was that over half of the participants over 65 years of age had not had access to services. The elderly represent a particularly vulnerable group and this group should be targeted in any attempt to expand services. However, it does not appear as if the cause of disability is associated with access, as 40–50% of those whose disability was caused by unintentional injury, maternal/child health factors or chronic diseases of lifestyle. Those with infectious diseases had had more access to services.

The number of people requiring rehabilitation for physical functional limitations was the highest, however the number of people requiring rehabilitation for limitations related to sensory and language functioning represented a larger proportion of those reporting unmet needs. It would appear that a range of services

need to be made more available, ranging from physiotherapy to speech and language therapy and audiology. The inadequate provision of assistive devices, including wheelchairs and walking aids reflects the disadvantage of the participants as these devices are readily available to those who do manage to access the public sector. This failure to access services was similarly identified by Sharma who reported that older African Americans “continue to remain in poorer health despite access to care and insurance status... (and that) underutilization accounts for some of this observed disparity” [12].

The limitations of the study include the need to rely on self-report which may have over- or under-estimated the need and/or access. A comparison of self-report, clinical examination and a standardised measure of work-related limitation for monitoring activity limitations, demonstrated a considerable differences in results. Self-reported limitations were higher than from those derived from clinical examination or the use of a standard measure of functional capacity [13].

However, the information relating to service need and utilisation may be equated with an assessment of the performance of the respondents and their interaction with environmental factors. This is defined in the ICF as “involvement in a life situation or the lived experience of people within the actual context in which they live” (P229) [1]. It is difficult to obtain objective data regarding these experiences and the researcher is usually reliant on self-report data, with all their limitations.

The results of this study indicate an urgent need to improve access to rehabilitation services, including the provision of assistive devices to people with disability living in this impoverished area. Physiotherapy and home based care in particular were identified as being required by several people. There seemed to be less awareness of the contributions of other rehabilitation professional and there may be a need to raise awareness of the role of speech and language therapists, audiologists, occupational therapists and psychologists. There is currently a programme underway to train home based carers to meet the needs of the community as identified through the larger study. However, it would be important that the training incorporate management of not only physical but sensory and language functional limitations as well. Prescription, supply and fitting of assistive devices may well be beyond the scope of the home based carers skills and as 35.5% reported the need for such devices, it may be important that the home-based carers be supported by a network of therapists who are able to guide, train and supervise their training and management of patients and who are able to provide specialist support where necessary.

The local authorities seem to have made reasonable headway with the provision of health care services; however the provision of rehabilitation services that would appear to impact positively on the QoL of people with disabilities is lagging behind. The Report suggests that, where services are minimal, basic rehabilitation services should be developed within the existing health infra-structure [2]. In the light of the relative accessibility of health care services, this might be a very useful strategy. The

training of home based carers as community-based rehabilitation workers is another strategy that could be employed, as discussed above. However, it should be remembered that South Africa is categorised as a middle and not a low-income country and the sophisticated service coverage available to those with higher incomes should ultimately be expanded and the service quality improved. The most disadvantaged people in the one of the most disadvantaged communities in Cape Town surely have the right to access appropriate care.

Declaration of interest

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of this article.

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