Original Research Article

Barriers in accessing rehabilitative services among person with disability in tertiary care hospital of Northern India: A descriptive cross sectional study

Awadhesh Kumar[1], Nikhil Sinha[2], Sandeep Mishra[3], Dhananjay Kumar Singh[4*], Pratibha Gupta[5], Vijay Kumar[6], Arshita Srivastava[7]

[1]Assistant Professor, Department of Community Medicine, Rajarshi Dashrath Autonomous State Medical College, Ayodhya, Uttar Pradesh, India
[2]Professor, Department of General Medicine, Heritage Institute of Medical Sciences, Varanasi, Uttar Pradesh, India
[3]Assistant Professor, Department of Community Medicine, Seth GSMC & KEMH, Mumbai, Maharshtra, India
[4]Associate Professor, Department of Community Medicine, Rajarshi Dashrath Autonomous State Medical College, Ayodhya, Uttar Pradesh, India
[5]Professor, Department of Community Medicine, Rajarshi Dashrath Autonomous State Medical College, Ayodhya, Uttar Pradesh, India
[6]Professor, Department of Plastic Surgery, Rajarshi Dashrath Autonomous State Medical College, Ayodhya, Uttar Pradesh, India
[7]Tutor, Department of Community Medicine, Rajarshi Dashrath Autonomous State Medical College, Ayodhya, Uttar Pradesh, India

Received: 22-09-2021 / Revised: 14-10-2021 / Accepted: 25-11-2021

Abstract

Background: Any restriction or lack of ability to perform an activity in a manner or within the range considered normal for the human beings, resulting from impairment is termed as disability. Impairment concerns the physical aspects of health; disability is the loss of functional capacity resulting from an impaired organ. **Aim and Objectives:** To study the socio-demographic profile of person with disability admitted in tertiary care hospital, To study the barriers in accessing rehabilitative services by person with disability in tertiary care hospital, To give recommendations on the basis of study findings. **Material and Methods:** It was a hospital-based cross-sectional study. All the patients admitted in department of physical medicine and rehabilitation were included in the study after taking written consent. A semi-structured questionnaire was prepared and pretested before conducting the actual study. Statistical analysis was done by SPSS (version 21) software. Participants' socio-demographic characteristics were described using descriptive statistics. **Results:** In the present study maximum person with disability were in the age group 11-30 years (59.8%) followed by age group less than oe equal to 10 years (27.5%). Present study shows that about two third (66.7 %) respondents were aware that facility for callipers and shoes on concession is available for BPL card holders . whereas one third (31.4%) were aware that investigation on concession is also available for BPL card holders. Only (18.6 %) were aware that surgery on concession is also available.

Keywords: Awareness, Barriers, Rehabilitative services, Person with Disability

Introduction

Any restriction or lack of ability to perform an activity in a manner or within the range considered normal for the human beings, resulting from impairment is termed as disability. Impairment concerns the physical aspects of health; disability is the loss of functional capacity resulting from an impaired organ[1]. Handicap is a measure of the social and cultural consequences of an impairment or disability. The types of disability include loco-motor, paraplegia, cerebral palsy.

People with disabilities are more vulnerable than general population to a range of problem including fatigue, depression, and social isolation and have more limited access to health care[2]. Evidences indicate that people with disabilities smoke more, and exercise less as compared to people not identified as having disabilities. The inability to perform some key activities (e.g. basic mobility, feeding, personal hygiene and safety awareness) due to disability lead to 'dependency' – the need for human help (or care) beyond that customarily required by a healthy adult. Such kind of help is given by family members or other 'informal' care givers[3]. Overall, a country is greatly affected by the increasing number of dependent people and would need to identify the human and financial resources to support them. This increase will occur more in the context of generally increasing population, and dependency ratios will increase modestly to about 10%. The dependency ratio would increase more in China (14%) and India (12%) than in other areas having more prevalence .The occurrence of disability is high in developing countries. It is among the poorest communities where poverty breeds disablement and disablement breeds poverty, a vicious cycle that the poor can least afford. The majority of people with disabilities find that their situation affects their chances of going to school, working for a living, enjoying

*Correspondence
Dr. Dhananjay Kumar Singh
Associate Professor, Department of Community Medicine, Rajarshi Dashrath Autonomous State Medical College, Ayodhya, Uttar Pradesh, India.
E-mail: drdksingh007@gmail.com

family life, and living normally like other people.. Quality of life is compromised not only for the disabled person, but also for the family[4]. The presence of one person with disability in a family has negative consequences of social stigma which affects the entire household. Social segregation of disabled person is also widespread. The mortality and morbidity among disabled is much greater as compared to people without disability. Although most of the disabilities can be prevented if proper preventive and rehabilitative measures of impairments are undertaken, it is estimated that only 2% of people with disabilities in developing countries have access to rehabilitation and appropriate basic services[5,6]. The purpose of this study is to understand the awareness and barriers in accessing health care services and rehabilitation services among people with disabilities.

Aim and Objectives of the study

1. To study the socio-demographic profile of person with disability admitted in tertiary care hospital.
2. To study the barriers in accessing rehabilitative services by person with disability in tertiary care hospital.
3. To give recommendations on the basis of study findings.

Material and Methods

Study Setting

The study was conducted in the department of Physical Medicine and Rehabilitation (PMR) of tertiary care hospital in Northern India over a period of one year.

Study Population

The study population of this study was patients admitted in Physical Medicine and Rehabilitation department of King George Medical University Lucknow during the study period of one year.

Study Design

Hospital based cross sectional study.

Sample Size

All the patients who were admitted in Physical Medicine and Rehabilitation department of tertiary care hospital in Northern India during the study period i.e. 102. Convenient sampling technique was used.

Inclusion criteria

Patients who were admitted in Physical Medicine and Rehabilitation department and ready to give consent for the study.

Exclusion criteria

Uncooperative patients.

Interview Schedule

The interview schedule was developed which had three sections consisting of socio demographic details, awareness and barriers in accessing rehabilitative services. The schedule was pretested for the accuracy of responses and to estimate time needed. The respondents were briefed about the survey in the local language. After consent, interview was conducted to fill the schedule.

Ethical Consideration

Verbal consent was taken from each selected participants to confirm willingness. Honest explanation of the survey purpose, description of the benefits and an offer to answer all enquiries was made to the respondents. Also affirmation that they are free to withdraw consent and to discontinue participation without any form of prejudice was made. Privacy and confidentiality of collected information was ensured throughout the process.

Results and Observations

Table 1: Socio Demographic profile of study participants (n=102)

Socio Demographic Characteristics		No	%
Age (years)	≤10	28	27.5
	11-30	61	59.8
	31-50	10	9.8
	≥ 51	03	2.9
Gender	Male	72	70.6
	Female	30	29.4
Religion	Hindu	85	83.3
	Muslim	17	16.7
Caste	General	27	26.5
	SC	30	29.4
	ST	1	1.0
	OBC	44	43.1
Type of Family	Joint	94	92.2
	Nuclear	05	4.9
	Single	02	2.0
	Second generation	01	1.0
Education	Illiterate because of disability	42	41.2
	Illiterate because of other reasons	04	3.9
	Primary School	24	23.5
	Middle School	21	20.6
	High School	00	00
	Secondary	10	9.8
	Graduate	00	00
	Post Graduate	1	1
Marital status	Married	24	23.5
	Unmarried	78	76.5

Table 1 shows that maximum participants were in the age group 11-30 years (59.8%), followed by in the age group less than or equal to 10 years (27.5%). The proportion of male (70.6%) was more than twice as compared to females (29.4%). Religion wise proportion of participants was almost the same as in the general population-Hindu (83.3%) and Muslims (16.7%).Caste wise distribution shows that maximum participants belonged to OBC (43.4%) followed by SC (29.4%) and general category, (26.5%). Majority of participants were living in joint families (92.2%) .Distribution on the basis of Education was as follows primary school (23.5%), middle school (20.6%) secondary (9.8%) and post graduate 1%. The percentage of married participants were (23.5 %)

Table 2: Distribution of study participants on the basis of type and cause of disability (n=102)

Type of disability	No	n(%)
Orthopaedic	102	100
Others	00	00
Cause of Disability		
Accidental (RTA)	56	54.9
Drug /vaccine related	09	8.8
Physiological	06	5.9
Congenital	20	19.6
Due to other reason	11	10.8

Table 2 shows that all Person with Disability had orthopaedic disability and half of them (54.9%) had acquired it by road traffic accident and about one fifth 19.6% were congenital.

Table 3: Barriers faced by person with disability in day today life.

Type of barriers faced	N	%
Transportation related		
Yes	77	75.5
No	25	24.5
Construction and building ramp related		
Yes	62	60.78
No	40	39.2
People attitude towards Person with Disability		
Yes	90	88.2
No	12	11.76
Barrier to entry to parks and malls		
Yes	80	78.4
No	22	21.56

Table 3 shows that many barriers were faced by person with disability in their day to day life like transportation (75.5%), ,construction and building ramp related(60.78%) people with not helping attitude towards study participants (11.76%) and barrier to entry to parks and malls (78.4%).

Table 4: Barriers faced by person with disability in accessing rehabilitative services

Factors	N	%
Unawareness	59	57.80
Financial problem	27	26.47
Family members non cooperative	10	9.80
Negligence	6	5.88

.

Table 4 shows that unawareness was the main reason for not availing rehabilitation services (57.80%). Financial problem, negligence and non – cooperation from family members contribute 26.47 %, 5.88% and 9.80 % respectively for not being offered rehabilitation services to disabled.

Discussion

The present study was undertaken to study the socio-demographic profile of disabled person admitted in the department of Physical Medicine and Rehabilitation King George's Medical University Lucknow and to determine the barriers faced by them regarding health care services and Rehabilitation service available for them. In the present study maximum Person with disability were in the age group 11-30 years (59.8%) followed by PWD in the age group less than or equal to 10 years (27.5%). In the present study it was observed that proportion of male PWD (70.60%) was more than twice than that of female (29.4%). Caste wise distribution shows maximum PWD belongs to OBC (43.1%) followed by SC (29.4%) and general (26.5%.) Majority of PWD were living in joint family (92.2%) ;(4.9%) were living in nuclear family, (2%) were single and (1%) were living in second generation. In present study (45.1%) PWD were illiterate; 23.5 had studied upto primary level; 20.6% attended middle school;9.8% studied up to secondary level and there was only 1 postgraduate. VijayKumar and Singh (2004) conducted a study among 36 PWD's who attended PMR, OPD of AIIMS New Delhi. They observed that 8.3% PWD's were illiterate 11.11% studied upto primary level, 28.8% have studied upto middle level.19.44 % studied upto higher level 22.22% were graduate[7]. In present study out of 102 PWD's 23.5% were married while remaining 76.5% were unmarried. It was observed that 41.2% belong to lower class 27.5% belongs to upper lower class, 17.6% belong to middle and 9.8% upper and only 3.9% belong to upper class. Vijaykumar and Singh (2004) observed in their study conducted on 36 PWD's that 11.11% belongs to low Socioeconomic scale,30.55 belong to middle income group[7].

In present study all 102 PWD had orthopaedic disability in about half of them 54.9% and cause of disability was Road Traffic Accident, followed by congenital 19.6%, drug/vaccine related 8.8% and physiological 5.9%.In remaining 10.8 percent due to other reason.

Srivastava etal studied physically disabled people of the rural population of district Mau in Uttar Pradesh they found that most prevalent physical disability was locomotor 10.44 per thousand[8]. It was observed in the present study that many barrier faced by PWD in day to day life like entry to park and malls 78.4%,transporatation 75.5%,construction and building ramp related60.78%,not helping attitude of people towards PWD 11.76%. In the present study it was observed that unawareness was the main reason for not availing rehabilitation services (57.80%). Financial problem, negligence and non – cooperation from family members contributed 5.88% and 9.80 % respectively for not being offered rehabilitation services to disabled.

Recommendations

1. Advocacy for mainstreaming the systems and services. It requires commitment across all sectors and built into new and existing legislation, standards, policies, strategies, and plans.
2. Invest in specific programs and services for people with disabilities. In addition to mainstream services, some people with disabilities may require access to specific measures, support services, or training. In this process, involvement of persons with disability is of paramount importance as they give insight into their problems and suggest possible solution.
3. Capacity building of health care providers and program managers. Human resource capacity can be improved through

effective education, training, and recruitment. A review of the knowledge and competencies of staff in relevant areas can provide a starting point for developing appropriate measures to improve them. Manpower generation by promoting new courses and initiating degree and diploma courses like Physical Medicine and Rehabilitation will address the problem of shortage of manpower in long run.

4. Focus on educating disabled children as close to the main stream as possible.
5. Increase public awareness and understanding of disability. Governments, voluntary organizations, and professional associations should consider running social marketing campaigns that change attitudes on stigmatized issues such as HIV, mental illness, and leprosy. Involving the media is vital to the success of these campaigns and to ensuring the dissemination of positive stories about persons with disabilities and their families.
6. Generating representative community-based data will help to plan and execute appropriate measures to address the problems of persons living with disability.
7. Strengthen and support research on disability.

Conclusion

Majority of disabled population in this study were illiterate and belonged to lower and backward caste. They were not aware of the available rehabilitation services and very poor access to available rehabilitation services. Thus it is recommended that an awareness program be devised and implemented to make the disabled aware of the available rehabilitation services. There should be a comprehensive health care package for the disabled such as special medical camps at the village level for cataract operations and periodic medical care for the other types of disabilities. Special arrangement should be made to accommodate them in small scale industries which can be home based or industrial based according to their capacity.

References

1. Health-related quality of life and activity limitation- Eight States, 1995. Morbidity Mortality Weekly Report 1998;47:134-40.
2. Medical Research Council Cognitive Function and Ageing Study (MRC CFAS); Resource Implications Study (RIS MRC CFAS). Profile of disability in elderly people: estimates from a longitudinal population study. BMJ 1999;318:1108-11.
3. Disability, Poverty and Development. Department for International Development Report. IHF Official Journal 2000;38:1.
4. Lollar DJ. Public Health and Disability: Emerging Opportunities. Public Health Rep 2002;117:131-6.
5. World Health Organization. Training in the community for people with disabilities. Geneva: WHO; 1989.
6. Pal HR, Saxena S, Chandrashekar K, Sudha SJ, Murty RS, Thara R, et al. Issues related to disability in India: A focus group study. Nat Med J India 2000;13:237-41.
7. Vijaykumar S. PWD Act: awareness among beneficiaries and members of rehabilitation team. *IJPMR.* 2004 ; 15:12–16
8. Srivastava D, Khan J, Pandey S, Pillai D, Bhavsar A. Awareness and utilization of rehabilitation services among physically disabled people of rural population of a district of Uttar Pradesh, India. Int J Med Sci Public Heal. 2014;3(9):1157.
9. Chauhan A et al. Disability and mortality following road traffic injury: a follow-up study from a tertiary care centre of India. Int J Community Med Public Health. 2017 Dec;4(12):4712-4717
10. Williams MH, Bowie C. Evidence of unmet need in the care of severely physically disabled adults. BMJ 1993;306:95-8.
11. Patel SK, Ladusingh L. Age pattern of onset of disability and treatment seeking behaviour of disabled persons in India. XXVI IUSSP International Population Conference. Available from: URL: http://iussp2009.princeton.edu/abstracts/91173
12. Hosain GM, Chatterjee N. Health care utilization by disabled persons: A survey in rural Bangladesh. Disabil Rehabil 1998;20:337-45.
13. D'Noveymony MA, Raj SS. A study in the family and socio-economic conditions of the persons with disabilities in Vallioor Panchayat Union. Asian Pac Disabil Rehabil J 2003;5:14-20.
14. Chopra A, Saluja M, Patil J, Tandale HS. Pain and disability, perceptions and beliefs of a rural Indian population: A WHO-ILAR COPCORD study. WHO-International League of Associations for Rheumatology. Community Oriented Program for Control of Rheumatic Diseases. J Rheumatol 2002;29:614-21.

Conflict of Interest: Nil Source of support: Nil