

Quality of Life among Persons with Physical Disability in Udupi Taluk: A Cross Sectional Study

Kunal Kuvalekar, Ramachandra Kamath, Lena Ashok, Bhartesh Shetty, Shreemathi Mayya¹, Varalakshmi Chandrasekaran

Departments of Public Health, ¹Biostatistics, Manipal University, Manipal, Karnataka, India

ABSTRACT

Background: Disability is not just a health problem or attribute of individuals, but it reflects the problems individuals experience in their interaction with society and physical movements. Disabled persons remain neglected part of society and they also experience various barriers due to restriction of participation. **Objectives:** The aim was to assess the quality of life (QOL) of physically disabled persons, the impact of physical disability on activities of daily living (ADL) and to study the awareness about laws and facilities available for disabled persons. **Materials and Methods:** A cross-sectional community based study was conducted among 130 physical disabled persons who were selected using convenience sampling technique. The WHO BREF scale was used to assess QOL, while assessment of ADL was done using Barthel Index. Socio-demographic assessment was done using Udai Pareek scale. SPSS version 15.0 was used to analyze data. Categorical variables were expressed as frequencies and percentages. As per guidelines physical, psychological, social, and environmental domain scores for WHO BREF scale were calculated. **Results:** Among the study participants, 36.2% had a disability from birth that is, congenital. The second common cause of disability was found to be postpolio residual paralysis as it was found among 26.2% respondents. Other causes found were stroke/paralysis and accidents, in 19.2% and 18.5% respondents, respectively. Activities such as transfer, mobility, and stair climbing showed greater impact of physical disability. It was found that 11.5% respondents required help in one of the ADL. QOL score was found to be low under the psychological domain reflecting on negative feelings, bodily image, appearance, spirituality, and self-esteem of respondents. **Conclusion:** Physical disability had affected social participation as well as marriage of the respondents. However, it was found that very few of them are aware about facilities provided under persons with disability act.

Keywords: Activities of daily living, physical disability, quality of life

Introduction

Disability is not just a health problem or attribute of individuals, but it reflects difficulties individuals may experience in interaction with society and physical movements.^[1] Disability term includes impairments, activity limitations and participation restrictions.^[2] The term “disability” has many different meanings; the global burden of disease (GBD) however, uses the term disability to refer to loss of health, where health is conceptualized in terms of functioning capacity in a set of health domains such as mobility, cognition, hearing, and vision.^[3] For disabled persons and their families situation becomes doubly difficult due to general health problem and unique social stigma attached to various types of disability.^[4] Disabled people experience various

barriers due to restriction of participation and their lives are affected with poor health outcomes, low education, lack of social and economic participation, higher rates of poverty and increased dependency.^[5]

Non-communicable diseases such as diabetes, cardiovascular diseases, mental disorders, cancer, and respiratory illness show increasing trends all over the world. These diseases have profound effects on disability.^[2] According to the WHO estimates 15% of world’s population has some form of disability and 2–4% of them experience severe difficulties in functioning. GBD 2004 data analysis showed that 15.3% of the world population (approximately 978 million people) had moderate or severe disability, while around 2.9% population (185 million people) experienced severe disabilities.^[3] The Millennium Development Goals (MDGs) represent a hard pressing effort to address global poverty. Yet there is a striking gap in the current MDGs as persons with disabilities

Access this article online

Quick Response Code:



Website:
www.jfmpc.com

DOI:
10.4103/2249-4863.152258

Address for correspondence:

Dr. Lena Ashok,
Department of Public Health, Manipal University, Madhav Nagar,
Manipal - 576 104, Karnataka, India.
E-mail: lenaashok@gmail.com

were not considered. The estimated 1 billion people worldwide who live with at least one or more type of disabilities that is, physical, sensory (blindness/deafness), intellectual or mental health impairments, are not mentioned in any of the 8 MDGs or 21 targets or 60 indicators, nor in the Millennium declaration. This absence is of particular concern because a growing consensus and awareness among disability advocates, experts, and researchers find that the most pressing issue faced globally by persons with disabilities is lack of equitable access to resources such as education, health care facilities, employment, social participation activities, and not their specific disability. This results in disproportionately high rates of poverty. The links between disability and poverty are noteworthy and size of the globally distributed disabled population makes these links of particular concern to all working on issues related to poverty.^[6]

According to 2001, census data India had 2.1% disabled population and disability in the movement was observed in 27.8% population.^[7]

Karnataka has a disabled population of 940,643 out of which 661,139 people live in rural areas, while 279,904 people live in urban areas. The literate disabled population was 473,844, which consisted of 51.40% of the total disabled population. Most of families with disabled persons live below the poverty line.^[8]

Rationale

There are many studies available on the prevalence of disabilities in India and mostly focus on the geriatric population. There are very few studies conducted among young adults. Furthermore, there is comparatively less literature available on the quality of life (QOL) among physically disabled persons. This study attempts to understand the QOL and other associated concerns among younger as well as the older population.

Objective

To assess the QOL among physically disabled persons, impact of physical disability on activities of daily living (ADL) and their awareness regarding laws and/facilities and utility pattern of available benefits in Udupi taluk, Karnataka.

Materials and Methods

A community-based cross-sectional study was conducted in Udupi taluk from February to July 2013. Sample size was calculated for estimation of scores of QOL. A total of 130 physically disabled persons registered under 16 panchayats in Udupi taluk were interviewed. Convenience sampling technique was adopted for the study. Respondents who were 18 years and above and permanently disabled were included in the study, while mentally challenged and severely ill were excluded. List of disabled persons was obtained from each of 16 panchayats. And physically disabled persons were selected with the help of multipurpose rehabilitative workers (MRW) and village rehabilitative workers.

Operational definition for physical disability

(a) Persons having locomotor disability (b) loss or absence or inactivity of whole or part of hand or leg or both due to amputation, paralysis, deformity or dysfunction of joints which affected his/her "normal ability to move self or objects" (c) those with physical deformities in the body other than limbs such as, hunch back, deformed spine. Dwarfs and persons with stiff neck of permanent nature who generally did not have difficulty in the normal movement of body and limbs were also treated as disabled.^[9]

The interview schedule was divided into three parts. A structured questionnaire adapted from Udai Pareek scale was used to assess socioeconomic status of study participants. WHO BREF scale^[10] was used to assess QOL of the study participants. For assessment of ADL, Barthel Index^[11] was used. The interview schedule was translated to the local language for better understanding by the participants. Ethical permission to conduct this study was obtained from Institutional Ethics Committee (IEC No. 134/2013). Written informed consent was obtained from each respondent prior to the interview.

WHO BREF scale had 26 questions, which were divided under four main domains namely: Physical, psychological, social and environmental. Barthel Index has 10 main ADL which included bowel habits, bladder habits, grooming, toilet use, feeding, dressing, transfer, mobility, stair climbing and bathing. SPSS version 15.0 (Chicago, IL) s used to analyze data. Categorical variables were expressed as frequencies and percentages.

Results

Table 1 shows that mean age of the respondents was 43.26 ± 14.6 years. Minimum and maximum age of the respondents was 18 and 76 years respectively. Majority of the respondents belonged to 25–44 years age group. Among the total 130 respondents, 89.2% were Hindus followed by 6.2% Muslims and 4.6% were Christians. Less than half that is, 46.2% of the respondents were single and reported that disability was main reason for remaining single. Majority of the respondents 67.7% were living in nuclear family while remaining 32.3% belonged to joint family. Approximately, one-fourth that is, 24.6% respondents were illiterate, while 46.9% of them were found to have primary education. There was only one female who was a graduate. Regarding occupational status of household of respondents, 62.3% were found to be unemployed. Only 5.4% respondents were skilled workers, while 7.7% were unskilled workers. Out of 130 respondents 70% respondents were living in pucca type houses. Only 18% and 12% respondents were living in mixed and kutcha type of houses, respectively. Most of the respondents (89.23%) belonged to low socioeconomic status with score of below 40, while 10.76% respondents were in middle socioeconomic status group. There were no respondents in higher socioeconomic

Table 1: Distribution of respondents according to their socio-demographic characteristics (n=130)

Variable	Male n=78, n (%)	Female n=52, n (%)	Total n (%)
Religion			
Hindu	67 (85.9)	49 (94.2)	116 (89.2)
Muslim	6 (7.7)	2 (3.8)	8 (6.2)
Christian	5 (6.4)	1 (1.9)	6 (4.6)
Marital status			
Single	36 (46.2)	24 (46.2)	60 (46.2)
Married	39 (50)	20 (38.5)	59 (45.4)
Separated	3 (3.8)	-	3 (2.3)
Widowed	-	8 (15.4)	8 (6.2)
Family type			
Nuclear	52 (66.7)	36 (69.2)	88 (67.7)
Joint	26 (33.3)	16 (30.8)	42 (32.3)
Education			
Illiterate	10 (12.8)	22 (42.3)	32 (24.6)
Primary	42 (53.8)	19 (36.5)	61 (46.9)
High school	17 (21.8)	8 (15.4)	25 (19.2)
Higher secondary	6 (7.7)	2 (3.8)	8 (6.2)
Diploma	3 (3.8)	-	3 (2.3)
Graduate	-	1 (1.9)	1 (0.8)
Participation in organization			
No participation	69 (88.5)	34 (65.4)	103 (79.2)
One organization	6 (7.7)	16 (30.8)	22 (16.9)
>1 organization	2 (2.6)	1 (1.9)	3 (2.3)
Wide public leader	1 (1.3)	1 (1.9)	2 (1.5)
Household occupation			
Unemployed	46 (59)	35 (67.3)	81 (62.3)
Unskilled	14 (17.9)	5 (9.6)	19 (14.6)
Semiskilled	3 (3.8)	7 (13.5)	10 (7.7)
Skilled	5 (6.4)	2 (3.8)	7 (5.4)
Business	9 (11.5)	3 (5.8)	12 (9.2)
Professional	1 (1.3)	-	1 (0.8)

class. Respondents are entitled to monthly financial assistance from the government. This was based on the degree of disability. Persons with disability ranging between 40% and 75% were entitled to get 400 rupees every month and with disability above 75% they were entitled to 1000 rupees every month. In this study, we found 60% of men and 59% of women were entitled to 400 rupees every month and 28% of men and nearly 33% of women were entitled to 1000 rupees every month [Table 1].

Figure 1 shows that among the study participants 36.15% had congenital disability. The second common cause of disability was found to be postpolio residual paralysis (PPRP) as it was seen among 26.2% respondents. It was also observed that males were affected more when compared to females. Other two causes of physical disability reported were stroke/paralysis and accidents, in 19.23% and 18.46% respondents, respectively.

Among 130 respondents, 17% of the respondents had one or other co-morbidities, hypertension being the most common (9.2%) followed by diabetes (3.8%) and asthma (1.5%).

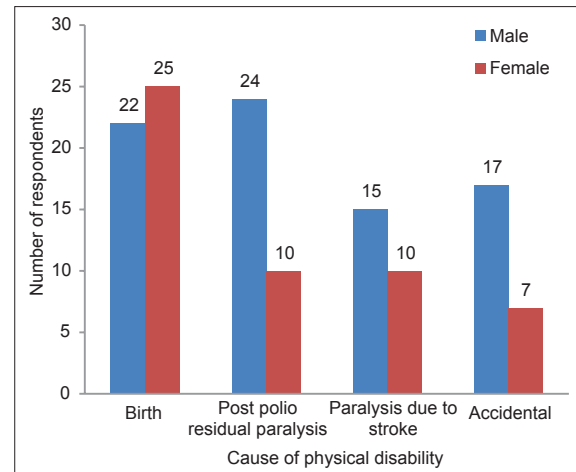
**Figure 1: Distribution of respondents according to type of disability (n = 130)**

Table 2 shows that activities such as transfer, mobility, and stair climbing showed greater impact of physical disability. Among 130 physically disabled persons interviewed, 43.8% respondents required minor help and 13.1% respondents required major help or were unable to transfer. Mobility of physically disabled persons was also affected to a certain extent. Around 4% were immobile, while 10.8% needed wheelchair and 36.9% needed help of a person for walking. Only one-fifth that is, 20.8% respondents reported no problem in climbing stairs independently. Maximum respondents (56.2%) required help in the form of verbal, physical or carrying aid to climb stairs. Approximately, one-fourth of the respondents that is, (23.1%) were unable to climb stairs.

In Table 3 overall the QOL of the respondents was assessed in different domains like Physical, Psychological, Social and Environmental by using WHO BREF scale. Highest maximum score that is, 100 was observed in social relationship domain. Minimum score of six was observed in physical, psychological and social domains each. Lowest median score was noted in psychological domain. Overall, QOL score was also found low in psychological domain reflecting on negative feelings, bodily image, appearance, spirituality, self-esteem and their thinking. Assessment of QOL score was done with respect to type of disability. Psychological domain score was observed to be low across all types of disabilities.

Discussion

The current study found that 46.2% participants were single. Similar finding was reported in a study conducted in Bangladesh where similar proportion (47.5%) of respondents were single.¹¹²

When proportions of respondents living in joint family were compared, study done in rural part of an adjacent district¹³ had reported higher proportion (78.2%) of respondents living in joint family, whereas in the present study it was observed that 32.3% were living in joint family.

Table 2: Distribution of respondents according to ADL (n=130)

Type of ADL	Activity	Number (%)
Bowel	Occasional accident	3 (2.3)
	Continent	127 (97.7)
Bladder	Occasional accident	11 (8.5)
	Continent	119 (91.5)
Grooming	Needs help	15 (11.5)
	Independent face/teeth wash etc	115 (88.5)
Toilet use	Dependent	4 (3.1)
	Needs help (can do some things alone)	43 (33.1)
	Independent	83 (63.8)
Feeding	Needs help	16 (12.3)
	Independent	114 (87.7)
Transfer	Unable	7 (5.4)
	Major help	17 (13.1)
	Minor help	57 (43.8)
	Independent	49 (37.7)
Mobility dressing	Immobile	5 (3.8)
	Wheelchair independent	14 (10.8)
	Walks with help of one person	48 (36.9)
	Independent	63 (48.5)
	Dependent	1 (0.8)
Stairs	Needs help	28 (21.5)
	Independent	101 (77.7)
	Unable	30 (23.1)
	Needs help (verbal or physical, carrying aid)	73 (56.2)
Bathing	Independent	27 (20.8)
	Dependent	23 (17.7)
	Independent	107 (82.3)

ADL: Activities of daily living

Table 3: QOL domain scores of respondents (n=130)

Domain	Minimum	Q1	Median	Q3	Maximum
Physical	6	42.50	50	63	88
Psychological	6	31	44	56	75
Social	6	25	50	56	100
Environmental	19	38	50	56	88

QOL: Quality of life

The present study revealed that 24% of respondents did not have any formal education. In a similar study done in Malaysia reported approximately similar percentage 26.8% of respondents with no formal education.^[14] In another study conducted in Nigeria on health related QOL in PPRP survivors reported 20.4% respondents never attended school.^[15]

Employment status of the respondents can be compared with the study conducted in Nigeria. Both studies had reported >60% of the respondents being unemployed.^[15,16]

Socioeconomic status of the respondents in the study was compared with studies conducted in rural community of Karnataka where 51% respondents belonged to middle socioeconomic class^[13] and 61% of them were from low socioeconomic class.^[17]

The study showed that 36.2% had disability from birth that is, congenital. The second cause of disability was found to be PPRP as it was found among 26.2% respondents. Other causes found were stroke/paralysis and accidents, in 19.2% and 18.5% respondents, respectively.

The study conducted in Uttar Pradesh showed 9.09% of physical disability occurring due to accidents and reported 4.9% to have PPRP as cause of physical disability, while 17.07% had Physical disability attributed to stroke.^[18]

Co-morbidities observed in this study when compared to a study conducted in Uttar Pradesh reported higher prevalence of hypertension (49%), followed by asthma (15%), and heart problems (5%).^[18]

This study showed that 11.5% respondents required help in one of the ADL domain, which is less compared with a study conducted in Nigeria which reported 28.3% respondents required help in one domain. The reason could be majority being the geriatric population in Nigerian study.^[16]

In the present study, assessment of QOL score was done with respect to type of disability. And QOL score was found to be low in psychological domain reflecting on negative feelings, bodily image, appearance, spirituality, self-esteem and their thinking. Psychological domain score was observed to be low across all types of disabilities. In a similar study carried out in Nigeria among physical disabled persons showed high QOL scores under all four domains namely physical health, psychological health, social health, and environmental domains.^[15]

In a study conducted in two provinces namely-Chiang Mai and Nakhon Ratchasima of Thailand QOL was reported to be at moderate level (79.3%).^[17]

Conclusion

M Persons had physical disability due to congenital followed by PPRP. Activities like transfer, mobility, and stair climbing showed greater impact of physical disability. It was also observed that majority of them are not dependent on others for their daily activities. Co-morbidities like hypertension and diabetes was also noted among respondents. The QOL was found poor among respondents in the psychological domain as compared to other domains. This could be mainly because of their physical appearance, which refrain from the participation in social gatherings and family functions. Regarding linking them to social protection schemes, the district authorities have made attempts to link them monthly financial assistance, however efforts need to be directed toward empowering them with knowledge on various social protection schemes and play a facilitative role so that it can be accessed easily without much difficulties.

Acknowledgment

I express my deepest thanks to Mr. Niranjana Bhatt, Mr. Madhusudan (MRW) and village rehabilitative workers of all panchayats for sharing their valuable time, assistance and interaction with subjects. I express my gratitude to Department for Disabled and Senior Citizens, District Office Udupi for providing the list of panchayats and disabled persons for the year 2012–2013.

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How to cite this article: Kuvalekar K, Kamath R, Ashok L, Shetty B, Mayya S, Chandrasekaran V. Quality of life among persons with physical disability in udupi taluk: A cross sectional study. *J Fam Med Primary Care* 2015;4:69-73.

Source of Support: Nil. **Conflict of Interest:** None declared.