International Journal of Community Medicine and Public Health
Nagaraja D et al. Int J Community Med Public Health. 2023 Oct;10(10):3764-3770
http://www.ijcmph.com
pISSN 2394-6032 | eISSN 2394-6040

DOI: https://dx.doi.org/10.18203/2394-6040.ijcmph20233113

Original Research Article

Quality of life and barriers to access healthcare services among persons with disability aged 18-59 years in the area of Sarjapur primary health centre: a cross sectional study

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Received: 26 July 2023
Accepted: 31 August 2023

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ABSTRACT

Background: Disability is defined as any restriction or lack of ability to perform an activity in the manner or within the range considered normal for a human being. Apart from the type and severity of disability, factors such as socioeconomic and marital status are associated with poor QOL life among the PWDs There are distinctive barriers in accessing healthcare services resulting into poorer health outcomes among PWDs.
Methods: The objective of the study was to assess the quality of life and barriers associated with access to healthcare services among adults with disabilities in the age group of 18-59 years. This was a cross-sectional descriptive study done in Sarjapur PHC area. The sample size was calculated as 100. Stratified random sampling was used with each village as a strata. WHO BREFQOL was used assess the QOL and a face validated tool was used to assess the barriers in accessing healthcare services
Results: Among the 100 PWDs interviewed, 56% were males and 44% were females. The mean age of the study group was 35.5+11.6years. The median (IQR) QOL scores in each domain was as follows: physical 15.1 (12.0, 18.1), psychological 14.0 (10.6, 16.6) social 16.6 (13.3, 18.6) and environmental 16.0 (13.5, 18.0). There was a significant association ($p<0.05$) between education and QOL, marital status with psychological and environmental domain. The important barriers to access health services were institutional barrier (18%), attitudinal barrier (9%) and environmental barrier (7%).
Conclusions: The overall QOL was poor among the study subjects. Institutional barrier was higher when compared attitudinal and environmental barrier.

Keywords: Persons with disabilities, Barriers, Quality of life

INTRODUCTION

According to the World Health Organization (WHO), Disability is defined as "any restriction or lack of ability to perform an activity in the manner or within the range considered normal for a human being''.[1] Disability is complex, dynamic, multidimensional and contested.[2] According to the Census 2011, there are 8 types of disabilities which include disability in seeing, disability in hearing, disability in speech, disability in movement, mental retardation, mental illness, others and multiple disabilities.[3] The international classification of functioning (ICF) 2001, replaces the term "Disability" with newer terms like impairment, activity limitation and participation restriction denoting the functional aspects of the interaction between individual (with a health condition)and their contextual factors (environmental and personal factors).[2] The WHO report 2011 puts the global burden of disability at 10-15% with more than a billion people who experiencing any form of disability.[2,4] According to the Census of India of 2011, the prevalence of disability is 2.21%.[5]

WHO defines QOL as an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.[6] According to the study done by Gnanaselvam et al in Tamil Nadu found that apart from the type and severity of disability, factors such as socioeconomic and marital status were significantly associated with poor quality of life among the people with disabilities. 37.5% rated their quality of life as poor and 92.4% experienced negative feelings often.[7] Access to health services means "the timely use of personal health services to achieve the best health outcomes.[8] People with disabilities experience poorer health and receive less access to health care and less quality care than those without disabilities. A person's environment has a huge impact on the experience and extent of disability. Inaccessible environments create disability by creating barriers to participation and inclusion.[2] According to Tomlinson et al and World Report on Disability, there is also an international evidence of distinctive barriers in accessing health care services among persons with disabilities across the globe and has shown poorer health outcomes than nondisabled persons.[4,9] Barriers to health services include,

Communication barriers are experienced by people who have disabilities that affect hearing, speaking, reading, writing, and or understanding.[10] Transportation barriers are due to a lack of adequate transportation that hinders a person's ability to be independent and to function in society. Public transportation may be unavailable or may be at inconvenient distances or locations.[10] Institutional barriers include laws, policies, strategies, legislation or practices that discriminate as well as inadequate employment laws and electoral systems including the challenges for persons with disabilities to vote. Lack of enforcement and political support for policies can also be a barrier for people with disabilities.[11] People with disabilities are more than twice as likely to report finding health care provider skills inadequate to meet their needs, four times more likely to report being treated badly and nearly three times more likely to report being denied care.[12] According to the WHO report on disability research in Uttar Pradesh and Tamil Nadu states of India, cost (70.5%), lack of services in the area (52.3%), and transportation (20.5%) were the top three barriers to using health facilities.[13] Knowledge and attitudes regarding barriers are very significant environmental factors, affecting all areas of providing services and social life. Creating awareness and challenging negative attitudes are often the first steps towards creating more accessible environments for persons with disabilities.[4]

Objectives

The objectives of the study were; to assess the quality of life among the study subjects among adults with disabilities in the age group of 18-59 years in the Sarjapur PHC area and to assess the barriers associated with seeking health care services.

METHODS

The study was a cross-sectional study done under the Sarjapur Primary Health Centre area, Anekal Taluk, Bangalore urban district from February 2019 to June 2019. The sample size was calculated based on 37.5% prevalence of poor quality of life and an absolute precision of 10% with 95% confidence interval, the sample size was 93.75 and which was rounded off to 100.[7] All Adults with disabilities in the age group of 18-59 years residing in the Sarjapur PHC area for atleast 2 years with identified domains of disability as per the definition used in census 2011 were included. Treatable causes of disability like Cataract were excluded from the study. All adults with disability between the age group of 18-59 years, currently residing for at least 2 years in the area of Sarjapur PHC area was listed village wise using the health management information system. The study group was then selected by Probability Proportional to Size (PPS) to the number of PWDs residing in each village. The study group was selected using simple random sampling from the list of adults with disability. Three study tools were used: A pre-tested interview schedule which included socio-demographic details was used. Socioeconomic status was classified according to Modified BG Prasad's classification 2019.[14] WHOQOL-BREF was used to assess quality of life which comprised of 26 items with four broad domains: physical, psychological, social, and environment.[15] The domain scores were scaled in a positive direction where higher scores denoted higher quality of life. The mean score of the items within each domain was used to calculate the domain score. The resulting scores ranged between 4-20.[16] A three item face validated structured interview schedule to assess the barriers in accessing healthcare services among PWDs consisting of Environmental barriers like accessing public transport, transportation cost, location of the hospital, finding reserved seats for PWD. Attitudinal barriers like communicating with the community health workers, negative behaviour of health care workers and changing the physician because of their behaviour and Institutional barriers like the timings of the hospital, waiting for long period in queue, finding difficulty in filling forms and guiding to different sections, priority in out-patient department, separate accessible toilet and billing discharge procedures. Written informed consent was obtained from each of the study subjects before recruitment into the study.

Data entry and analysis

The data was then entered in Microsoft Excel and analyzed using Statistical package for the social sciences (SPSS) version 16. The continuous variables were analysed using mean and standard deviation; Categorical variables were analysed using percentages. The association between various factors was analysed using Chi square test, Fisher's exact test as applicable. A $p<0.05$ was considered statistically significant for all the analysis.

RESULTS

The (Table 1) shows the socio-demographic details of the study participants, 56% were males and 44% were females.

Table 1: Socio-demographic details of the study subjects (n=100).

Variable	Category	N (%)
Age (years)	18-28	31 (31)
	29-39	27 (27)
	40-50	29 (29)
	51-59	13 (13)
Gender	Males	56 (56)
	Females	44 (44)
Religion	Hindu	91 (91)
	Muslim	9 (9)
Education	Not gone to school	43 (43)
	Upto Middle school	20 (20)
	High school	21 (21)
	Pre-University and above	16 (16)
Employment status	Gainfully employed	47 (47)
	Unemployed	53 (53)
Marital status	Married	50 (50)
	Single	42 (42)
	Widow/er	6 (6)
	Separated	2 (2)
Type of family	Nuclear	69 (69)
	Joint	16 (16)
	Extended	6 (6)
	Three generation	9 (9)
Socioeconomic status	Upper class	48 (48)
	Upper middle class	36 (36)
	Middle class	8 (8)
	Lower middle class	7 (7)
	Lower class	1 (1)

Most of them 31% were in the age group of 18-28 years. About 43% had not gone to school and 16% completed pre-university and above. It was observed that 47% were gainfully employed and 50% were married with mean years of married life being 17.5±8.0 yrs. Nearly 69% belonged to nuclear family with 48% belonging to upper class. More than half of the participants had disability in movement 59%, intellectual disability 24%, speech 18%, hearing 12%, visual 11% and mental illness 3%. The median (IQR) Quality Of Life (QOL) scores in each domain was 15.1 (12.0, 18.1) in physical domain, 14.0 (10.6, 16.6) in psychological domain, 16.6 (13.3, 18.6) in social domain and 16.0 (13.5, 18.0) in environmental domain. The (Table 2) shows association between socio-demographic details and QOL. A significant association was found between education and quality of life, higher the educational status, better the quality of life in physical (p value=0.001), psychological (p value=0.001), social (p value=0.001) and environmental (p value=0.002) domains. There was also significant association between employment status and QOL in physical (p value=0.000), psychological (p value=0.000), social (p value=0.000) and environmental (p value=0.002) domains. Married subjects had better psychological (p value=0.000) and environmental (p value=0.006) quality of life. The association of socioeconomic status with quality of life showed study subjects in lower class had better environmental domain of quality of life with p value=0.003. There was no significant association between type of disability and QOL (Table 3). The (Table 4) shows the barriers in accessing healthcare services. Most of them 18% had institutional barrier, followed by 9% attitudinal barrier and 7% had environmental barrier. Among the study subjects having environmental barrier, everyone had lack of public transport, hospital and 42.9% had barrier due to reserved seats in public transport. Among the study subjects with attitudinal barriers, everyone reported the negative behaviour of the treating physicians and 33.3% had changed their physician because of their behaviour. Among the study subjects with institutional barriers, 83.3% had barrier due to long queue in reception counter followed by 77.8% had barrier in filling the forms and guiding to different sections, 61.1% were not giving priority in the OPD shown in (Table 5).

DISCUSSION

In this study 31% of the study subjects were in the age group of 18-28 years. According to the report of National Sample Survey, 17% of the disabled population is in the age group 10-19 years and 16% of them are in the age group 20-29 years.[5] The proportion of males was 56% and females were 44% among the study subjects. Our study results are almost similar to the 2011 Census data on disability, which shows the proportion of males being 55.9% and females being 44.1%.[3] Higher proportion of disability among males in our study might have been because in rural areas there is a stigma associated towards females with disability, lack of adequate care leading to premature death. In this study more than three fourth (91%) of the subjects were Hindu by religion and 9% were Muslim. This is consistent with the fact that the study area has predominantly Hindu families. This is also in concurrence with 2011 census, which mentions that 79.8% of population in India are Hindus.[17] In our study 43% had not gone to school, 6% had completed primary school**,** 14% middle school**,** 21% had completed high school, 9% Pre-University, and 7% had bachelor's degree. The proportion of educated was higher among the younger age group, probably due to the introduction of Sarva Shikshana Abhiyan which makes education free and compulsory for all, even though it was not statistically significant. The reasons for not going to schools in our study could be lack of teachers with training in special education, inaccessible schools, transport facilities and lack of infrastructure. The complete accessibility of schools and college campuses is still a challenge. In our study half of them 50% were married, 42% were unmarried, 6% were widow and 2% were separated from their spouses which is almost similar to the study done by Kuvalekar et al in Udupi Taluk among the PWDs 50% were married, 46.2% were single or unmarried 3.8% were separated.

Table 2: Association between various socio-demographic factors and various domains of quality of life (n=100).

Variables	Category N (%)	Physical	Psychological	Social	Environmental
Gender	Male 56 (56)	14.8 (11.4, 18.2)	14 (10.6, 17.3)	17.3 (13.6, 18.6)	16.5 (14.1, 18.0)
	Female 44 (44)	15.4 (12, 17.7)	13.6 (10.6, 16.6)	15.3 (13.3, 18.6)	15.2 (13.5, 17.8)
	P value*	0.827	0.604	0.455	0.244
Education	Not gone to school 43 (43)	13.1 (8.5, 16.0)	11.3 (8.6, 14.6)	14.6 (10.6, 18.6)	15 (12.0, 17.0)
	Upto middle school 6 (6)	14.8 (12.0, 18.8)	14.3 (12.1, 15.8)	16 (13.3, 18.6)	15 (12.6, 17.3)
	High school 14 (14)	17.1 (12.5, 17.7)	16 (14.0, 18.6)	17.3 (17.3, 18.6)	17.5 (16.2, 18.7)
	Pre university and above 21 (21)	18 (15.5, 18.8)	16.3 (13.3, 17.8)	18 (16.0, 18.6)	16.5 (14.6, 18.5)
	P value**	0.001	0.001	0.001	0.002
Marital status	Married 50 (50)	16 (12.5, 18.2)	15.3 (13.3, 18.0)	17.3 (14.6, 18.6)	17 (15.0, 18.5)
	Unmarried 42 (42)	13.7 (9.1, 18.4)	11.3 (8.0, 14.8)	15.3 (11.6, 18.6)	14.5 (11.5, 18.0)
	Widow 6 (6)	12.8 (7.2, 15.7)	11.3 (8.3, 15.8)	14 (12.0, 15.3)	14 (10.8, 16.2)
	Separated 2 (2)	15.4 (13.7, 17.1)	13.6 (13.3, 14.0)	18 (17.3, 18.6)	14.5 (14.5, 14.5)
	P value**	0.198	0.000	0.051	0.006
Type of family	Nuclear 69 (69)	14.8 (11.1, 18.0)	14 (10.6, 16.6)	16 (13.3, 18.6)	5.5 (13.0, 18.0)
	Joint 16 (16)	16.5 (11.2, 18.5)	13.6 (8.1, 16.8)	17.3 (13.6, 20.0)	16.2 (14.6, 17.8)
	Extended 6 (6)	15.4 (13.1, 17.4)	13.6 (10.3, 18.1)	16 (14.6, 18.0)	16 (12.6, 17.7)
	Three Generation 9 (9)	15.4 (13.4, 19.1)	18 (14.0, 19.0)	18.6 (16.6, 18.6)	16.5 (14.2, 19.5)
	P value**	0.701	0.075	0.154	0.540
Employment status	Gainfully employed	17.7 (14.8, 18.8)	16.0 (14.0, 18.6)	17.3 (16.0, 18.6)	17.0 (14.5, 18.5)
	Unemployed	12.5 (9.1, 15.7)	11.3 (8.3, 14.6)	14.6 (12.0, 18.0)	15.0 (11.7, 17.0)
	P value*	0.000	0.000	0.000	0.002
Socioeconomic status	Upper class 48 (48)	16.0 (12.7, 18.8)	15.0 (11.3, 18.0)	17.3 (14.6, 18.6)	16.5 (14.5, 18.5)
	Upper middle class 36 (36)	13.7 (11.4, 17.5)	14.3 (10.6, 16.0)	16.0 (13.6, 18.6)	15.5 (13.7, 17.5)
	Middle class 8 (8)	16.0 (10.7, 18.1)	12.3 (10.8, 15.0)	16.0 (11.3, 18.3)	13.7 (11.6, 14.8)
	Lowe middle class 7 (7)	13.1 (7.4, 15.4)	8.6 (7.3, 12.0)	13.3 (12.0, 20.0)	11.5 (7.5, 14.0)
	Lower class 1 (1)	17.7 (17.7, 17.7)	13.3 (13.3, 13.3)	20.0 (20.0, 20.0)	18.0 (18.0, 18.0)
	P value**	0.368	0.066	0.479	0.003

*Mann Whitney U test, **Kruskal Wallis test.

Table 3: Association between various domains of disability and quality of life (n=100).

Disability domain	Physical	Psychological	Social	Environmental
Seeing	15.4 (12.5, 17.7)	14.6 (11.3, 16.0)	16 (13.3, 17.3)	15.5 (14.0, 18.5)
Speech and Hearing	16.5 (12.5, 19.4)	14 (13.3, 17.3)	17.3 (10.6, 17.3)	17.5 (16.0, 18.0)
Movement	14.2 (12.0 ,17.7)	14.6 (11.3, 18.0)	17.3 (14.6, 18.6)	16.5 (14.5, 18.0)
Mental Retardation	14.8 (10.0, 17.2)	11.0 (6.6, 14.1)	14.0 (9.3, 17.6)	15.0 (13.0, 16.1)
Multiple disabilities	15.4 (12.0, 19.4)	14.0 (10.6, 16.6)	18.6 (13.3, 20.0)	14.5 (11.5, 18.0)
P value (Kruskal Wallis test)	0.490	0.065	0.135	0.310

According to the Census 2011 data, 46.87% of the total PWDs were currently married, whereas 41.72% are never married and 10.29% of them were widowed.[5,18] Out of 50% married subjects in our study 11% were married for 21-25 years, and 2% for more than 31 years. The proportion of males being married was higher when compared to females and was found to be statistically significant. The acceptance in the Indian society for a male with disability is better than women with disability. In countries with dowries, family has to pay more to marry their disabled daughters or alternatively they have to marry them to a family which is below their social standing in order to find a partner who is willing to take care of them.[19]

Table 4: Classification of barriers among the study subjects (n=100).

Variable	Environmental barrier N (%)	Attitudinal barrier N (%)	Institutional barrier N (%)
To some extent	4 (4.0)	8 (8.0)	16 (16.0)
To large extent	3 (3.0)	1 (1.0)	2 (2.0)
Total	7 (100.0)	9 (100.0)	18 (100.0)

Table 5: Different aspects of barriers among the study subjects (n=100).

Variables	Category	Not at all, N (%)	To some extent, N (%)	To large extent, N (%)
Environmental barriers (N=7)	Lack of public transport	0 (0.0)	5 (71.4)	2 (28.6)
	Affordable for transportation	6 (85.7)	1 (14.3)	0 (0.0)
	Location of hospital	6 (85.7)	0 (0.0)	1 (14.3)
	Reserved seats for PWD in public transport	4 (57.1)	1 (14.3)	2 (28.6)
Attitudinal barriers (N=9)	Communication difficulties with health workers	9 (100)	0 (0,0)	0 (0,0)
	Negative attitude of health workers	9 (100)	0 (0,0)	0 (0,0)
	Negative attitude of the treating physician	0 (0.0)	7 (77.8)	2 (22.2)
	Change in doctor because of his behaviour	6 (66.7)	2 (22.2)	1 (11.1)
Institutional barriers (N=18)	Timings of hospital	14 (77.8)	4 (22.2)	0 (0,0)
	Long queue in reception counter	3 (16.7)	14 (77.8)	1 (5.6)
	Filling forms and guiding to different sections	4 (22.2)	12 (66.7)	2 (11.1)
	Priority in OPD	7 (38.9)	9 (50)	2 (11.1)
	Separate accessible toilets	15 (83.3)	2 (11.1)	1 (5.6)
	Billing and discharging difficulties	8 (44.4)	9 (50)	1 (5.6)

Culturally in India it is acceptable to have a male with disability and the expectation is that the female should be physically and mentally healthy, since she bears the child and sole responsible for continuation of the family linage. More than half of our study subjects 53% were unemployed, which is almost similar to the study done by Kuvalekar et al among PWDs which is 59% were unemployed and 1.3% were professional.[18] According to Modified B. G. Prasad Socio-economic scale 2019, 8% of our study subjects belonged to upper class, 17% belonged to upper middle class, 12% to middle class and 63% of the study participants belonged to lower socio-economic class. Socioeconomic status comprises not only income but also educational attainment, financial safety, and subjective perceptions of social status and social class.[20] Analysis of the World Health Survey data for 15 developing countries suggests that households with disabled members spend relatively more on health care than households without disabled members. The educational attainment is low in our study which could be the possible reason for low socioeconomic status.[2] The proportion of employed was significantly higher among males as compared to females. According to the WHO report on Disability 2011, men with disabilities are twice as likely to have jobs compared to females.[2] In our study median overall QOL scores was found to be low in psychological domain 14.0 (10.6, 16.6) as compared to other domains which reflects negative feelings, bodily image, appearance, spirituality, self-esteem and thinking. This may be due to the perception of impairment or deformity among the study group. The association between various domains of disabilities and quality of life showed that psychological domain score was found to be low which is similar to the study done by Kuvalekar et al in Udupi among adults with disability.[18] It has been shown that chronic diseases are associated with low psychological health.[18,21] In our study 95% of the study subjects were found to have at least one co-morbidity which might have led to the low psychological score. According to the study done by Norfazilah et al in rural Selangor, Malaysia among young normal adults, the QOL scores were substantially higher than our study group.[21] A study done in Brazil by Mattevi et al on quality of life and care among disabled, it was found that the negative attitude towards PWD was one of the important factor that hinder their inclusion in social, economic, political and culture life, thus reducing their QOL.[22] In our study there was a significant association between education and quality of life, higher the educational status, better the quality of life in all domains. It was also seen that there was a significant association between gainful employment and educational status. It was also seen that there was a significant association between employment and quality of life; gainfully employed subjects had better the quality of life in all domains when compared with unemployed subjects.

Studies have shown that higher monthly income was positively associated with scores in the psychological, social relationships and environmental domains of QOL.[23-25] Higher income can be linked to many aspects of better patient care, such as prompt treatment, access to better rehabilitation and having less worry about the financial burdens of treatment and absence from work.[23] Friends and colleagues at the workplace, financial support due to employment play a crucial role in increasing the QOL.[26] In our study married subjects had significantly better psychological and environmental domain because of family life and having partner provides feeling of safety, being secured and the connectedness influencing better QOL.[21] The two important aspects to have a better life is having a supportive family and a good social life with empathetic friends.[27] The constant financial and emotional support from the partner, family and work or school mates influence the QOL.[22,28]

Our study found that 7% had environmental barrier like barrier in accessing public transport, affording transportation cost, location of the hospital and difficult in finding reserved seats for themselves. Barrier to access public transport could be due to unavailability or far distance of bus stops.[10] For all the countries, 28-29% of all PWDs suffer catastrophic expenditures compared with 17-18% of nondisabled people.[2] Our study reported 9% had attitudinal barrier like negative behavior of their treating physician. Attitudinal barriers is a result of how persons without disabilities distinguish persons with disabilities. Persons with disabilities habitually face prejudice and discrimination and often assume that they are incapable and unintelligent. Persons without disability treat them with pity.[29] In our study 18% had institutional barrier among like timings of the hospital, waiting for long period in queue, difficulty in filling forms and guiding to different sections, they were not given priority at out-patient department, couldn't find separate accessible toilet and difficulties in billing and discharging process. According to the world report on disability about 51-53% of people with disabilities are unable to afford health care compared to 32-33% of non-disabled people and according to the WHO report on disability research in Uttar Pradesh and Tamil Nadu states of India, cost (70.5%), lack of services in the area (52.3%), and transportation (20.5%) were the top three barriers to using health facilities.[4,13]

Limitations

The first limitation is the sample size calculated was small and the second is the QOL questionnaire were asked to the care givers of persons with intellectual disability instead of study groups

CONCLUSION

The overall QOL is poor among the study subjects. Institutional barrier was higher when compared attitudinal and environmental barrier.

Recommendations

National programs on disability should target the provision of inclusive educational and occupational opportunities with the aid of assistive technologies for people with disabilities, for improvement of quality of life. Governments can improve the health of people with disabilities by improving access to quality, affordable health care services, which make them the best use of available resources.

Funding: No funding sources
Conflict of interest: None declared
Ethical approval: The study was approved by the Institutional Ethics Committee

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Cite this article as: Nagaraja D, Shanbhag DN. Quality of life and barriers to access healthcare services among persons with disability aged 18-59 years in the area of Sarjapur primary health centre: a cross sectional study. Int J Community Med Public Health 2023;10:3764-70.