

Evaluating Quality of Life of Parents Having a Child with Disability

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ABSTRACT:

Introduction: Disability is the condition of difficulty in carrying out daily activities normally and in taking part in social life due to problems in parts of the body and the physical system. Children with disabilities are one of the most marginalized and excluded groups in society. Facing daily discrimination in the form of negative attitudes, Estimates suggest that there are at least 93 million children with disabilities in the world, but numbers could be much higher.

Method: A descriptive analytical research design was used to identify the quality of life of parents/caretakers having a child with disability/ies in Illam district. Systematic random sampling was used and collected data from 244 participants. World Health Organization Quality of Life-Brief (WHOQOL-BREF) Questionnaire was adopted. Association between the socio-demographic variables and four domains of WHOQOL was determined using one way ANOVA. In the end, multiple linear regression analysis was performed to find the predictors of domains of WHOQOL and to control the confounding effect.

Results: The quality of parents having a child with disability have good quality of life in social relationship mean 15.6 ± 1.3 . The physical domain is weakly correlated with the social domain. There is a moderate positive correlation between psychosocial and the social domains. Cognitive disability mean score was highest on social domain that is 14.91 and lowest on the physical domain (13.87).

Conclusion: To improve quality life of parents, health care and welfare professionals should focus on particular people with higher age group, disadvantaged and marginalized groups illiterate, those who are unmarried, divorced or separated and those engaged in agriculture and carry out interventions aimed at improving their quality of life.

Key words: Parents /care taker, Quality of life, Children with disability

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INTRODUCTION

Disability can be stated as restriction or loss of ability in performing an activity in appropriate manner or way due to impairment in body function or structure. Such condition leads an individual in activity limitation and difficulty in executing a task or action.¹ Disability also creates difficulty in functioning daily activities normally.² A child with a disability means a child who has mental or physical inability either congenital, caused by injury or because of any diseases. Such disabilities can be like mental retardation, hearing impairment, speech or language impairment, specific learning disability or deaf-blindness an individual with disability.³

More than one billion people live with a disability. About 110 million people (2.2% of the global population) have very severe functional difficulties. Among them, 80% of people with disabilities live in developing countries.⁴ Children aged between 0–14 years experiencing “moderate or severe disability” at 93 million (5.1%) and 13 million (0.7%) of children experiencing severe difficulties because of various disability.⁵ In 2005, UNICEF estimated that the number of children with disabilities under age 18 at 150 million. Recent study findings conducted in developing countries reports child disability prevalence ranges from 0.4% to 12.7%.¹ The implications of caring for a child with disability/ies are considerable and have profound effects on the entire family who may be parents, siblings, and

other extended family members. Because of dependency, in providing high-quality care required by a child with long-term functional limitations can influence the health and quality of life (QOL) among the caregivers.⁶

Children’s disabilities and distresses may burden to their family members, especially their parents, who are their long-term care providers. This may affect their parents’ quality of life as they need to spend most of their time in taking care of such child. So, such parents are unable to engage in other activities and diminish their social life which negatively affects their quality of life.⁷

MATERIALS AND METHOD

A descriptive exploratory research design was used to identify the quality of life of parents/caretakers having a child with disability/ies. The study was conducted in Illam district. The Study population included parents or caretakers having a child with disability/ies. Systematic random sampling was used and collected data from 244 participants. World Health Organization Quality of Life-Brief (WHOQOL-BREF) Questionnaire was adopted and basic modification was done according to research objectives. For the use of the tools in the Nepalese context, forward translation (from English to Nepali) and backward translation (from Nepali to English) was done. After the submission of formal written letter from the concerned authority Institutional review

committee of the Nepalese Army Institute of Health Sciences provided ethical approval for the study. One day orientation about the use of the tool was given to the enumerators. Data was collected from 2076/04/15 to 2076/6/15. All the respondents were interviewed by face to face interview method by using semi-structured interview schedule after taking written consent. After complete checked of

collected data, it was coded, classified and entered through SPSS version 20 for data analysis. Association between the socio-demographic variables and four domains of WHOQOL was determined using one way ANOVA and multiple linear regression analysis was performed to find the predictors of domains of WHOQOL and to control the confounding effect.

RESULTS

Among the participants, more than three-fifths (63.6%) of the participants were in the age group of 31 to 50 years with age ranging from 14 to 84 years. The majority (64.3%) of the participants were *Janajati*, followed by 27% of *Bramhin/Chhetri* and 8.2% *Dalit* participants. Regarding sex, two-thirds (66.4%) of the participants were female. The majority (90.6%) of the participants were married as regard to their marital status. More than one fourth (31.1%) of the participants were illiterate or had informal education whereas more than one third (35.7%) had completed secondary education. Agriculture was the main occupation of the participants (697%). Among the participants, about two-thirds (65.6%) were from the nuclear family (table 1).

Table 1: Socio-demographic characteristics of the participants

Characteristics (n=244)	No	Percent
Age		
≤30 years	42	17.2
31 to 40 years	88	36.1
41 to 50 years	67	27.5
> 50 years	47	19.3

Range (14-84) years		
Ethnicity*		
Dalit	20	8.2
Janajati	157	64.3
Brahmin/Chhetri	66	27.0
Sex		
Female	162	66.4
Male	82	33.6
Marital status		
Unmarried	14	5.7
Married	221	90.6
Separated	2	0.8
Widow	7	2.9
Education		
Illiterate or informal education	76	31.1
Primary education	68	27.9
Secondary education	87	35.7
Higher secondary and above	13	5.3
Occupation		
Agriculture	170	69.7
Business/labor/GO/others	28	11.5
Student/Housewife/Not earning	46	18.9
Type of family		
Nuclear	160	65.6
Joint	84	34.4

*include others (0.4%)

Table 2: WHOQOL-BREF domains of the study participants

Domains	Minimum	Maximum	Mean
Physical health	9.1	16.6	13.6±1.4
Psychological	6.7	18.7	12.6±1.8
Social relations	8.0	20.0	15.6±1.3
Environmental	6.5	16.0	11.9±1.7

Abbreviation: WHOQOL-BREF: World Health Organization Quality of Life-BREF

As presented in Table 2, the mean scores for physical, psychological, social relationships

and environmental domains are 13.6 (SD=1.4), 12.6 (SD=1.8), 15.6 (SD=1.3) and 11.9 (SD=1.7) respectively.

Table 3: Mean scores of quality of life domains among different subgroups (transformed scores 4-20)

Characteristics	Domains of quality of Life (mean± SD)			
	Physical	Psychological	Social	Environmental
Age				
≤30 years	13.8±1.2	12.7±1.5	15.6±1.3	12.5±1.2
31 to 40 years	14.0±1.2	13.2±1.6	15.8±1.5	12.1±1.7
41 to 50 years	13.5±1.3	12.5±1.9	15.6±1.2	11.8±1.6
> 50 years	12.8±1.5	11.8±1.7	15.1±1.2	11.3±1.6
<i>P value</i>	<0.001	<0.001	0.078	<0.05
Ethnicity				
Dalit	13.8±1.1	12.5±1.3	15.4±2.0	11.7±1.2
Janajati	13.5±1.3	12.4±1.6	15.6±1.1	11.9±1.6
Brahmin/Chhetri	13.7±1.5	13.2±2.0	15.6±1.5	12.2±1.9
<i>P value</i>	0.606	<0.05	0.924	0.181
Sex				
Female	13.6±1.5	12.6±1.8	15.5±1.2	11.9±1.8
Male	13.6±1.1	12.6±1.7	15.7±1.5	11.9±1.5
<i>P value</i>	0.931	0.906	0.476	0.933
Marital status				
Unmarried	13.4±1.4	12.7±2.1	14.9±1.4	12.5±1.7
Married	13.6±1.3	12.6±1.7	15.7±1.2	11.9±1.6
Separated	14.0±0.4	12.0±0.9	12.0±5.7	11.0±2.8
Widow	12.7±1.6	12.6±1.8	14.5±1.2	11.2±2.3
<i>P value</i>	0.360	0.960	<0.001	0.321
Education				
Illiterate or informal education	13.2±1.5	12.0±1.7	15.2±1.5	11.2±1.5
Primary education	13.6±1.3	12.6±1.8	15.8±1.2	12.0±1.6
Secondary education	13.9±1.2	13.1±1.7	15.7±1.3	12.4±1.7
Higher secondary and above	13.7±1.3	13.1±1.1	15.4±1.0	12.6±1.7
<i>P value</i>	<0.05	<0.001	<0.05	<0.001
Occupation				
Agriculture	13.5±1.3	12.5±1.8	15.7±1.2	11.8±1.6
Business/labor/GO/others	13.7±1.3	13.0±1.9	15.0±1.9	12.4±1.9

student/housewife/not earning	13.8±1.5	12.9±1.2	15.4±1.4	12.0±1.6
P value	0.347	0.196	<0.05	0.225
Type of family				
Nuclear	13.6±1.4	12.7±1.7	15.6±1.4	11.8±1.7
Joint	13.6±1.3	12.6±1.8	15.5±1.2	12.1±1.6
P value	0.692	0.638	0.770	0.239

The mean score of four domains of WHOQOL-BREF according to age, ethnicity, sex, marital status, occupation and type of family are presented in Table 3. Mean score of physical, psychological and social domains was higher for parents/caretakers of age group 31 to 40 years but higher mean score of environmental domain was observed in parents less than or equal to 30 years of age. For ethnicity, higher mean score of all domains was observed among Brahmin/Chhetri. Mean scores of physical and psychological domains was lower among Janjatis whereas for social and environmental domains, the score was lower among Dalit. Regarding sex, the mean scores were almost equal among male and female.

In regard to their marital status and occupation, there was fluctuation in the mean scores across domains. The mean score of psychological and environmental domains were higher for unmarried parents/caretakers while the mean scores of physical and social relationships were higher for separated and married. Regarding their education, the mean score of physical domain was higher for parents/caretakers having completed

secondary education. Similarly, mean score of psychological domain was higher and equal for parents/caretakers having their secondary and higher secondary and above education completed while the score of environmental domain was higher among parents/caretakers who have completed higher secondary and above education.

However, mean score of social domain was higher among those parents/caretakers who have completed primary education. Mean score of physical domain was higher for students, housewife and those not engaged in any occupation and lower for parents/caretaker who was engaged in agriculture. For psychological and environmental domains, the mean score was higher for those who were involved in business/labor/government organizations and lower for parents/caretaker involved in agriculture. Mean score of social relationships was higher for parents/caretaker engaged in agriculture and lower for those who were involved in business/labor/government organizations. The mean scores of physical, psychological and social relationships were almost similar for nuclear and joint families while the score was higher in parents/caretaker

living in joint family for environmental domain.

Table 4: Correlation between four domains of WHOQOL-BREF

Domains		Physical	Psychological	Social	Environmental
Physical	Pearson Correlation	1	0.432	0.041	0.336
	Sig. (2-tailed)		<0.001	0.520	<0.001
Psychological	Pearson Correlation		1	0.133	0.517
	Sig. (2-tailed)			<0.05	<0.001
Social	Pearson Correlation			1	0.125
	Sig. (2-tailed)				0.051
Environmental	Pearson Correlation				1
	Sig. (2-tailed)				

Correlation between four domains of WHOQOL-BREF was presented in table 3. Among the four domains of WHOQOL-BREF, three domains namely physical, psychological and environmental were significantly and positively correlated with low to high relationships ($r=0.336-0.517$, p value <0.001). However social relationship domain was only found to be correlated with psychological domain with low relationship ($r=0.133$, p value <0.05).

Table 5: Multiple linear regression analysis of factors associated with different domains of WHOQOL

WHOQOL domains		Unstandardized Coefficients		Standardized Coefficients	t	p value
		Beta	Std. Error	Beta		
Physical	Age	0.589	0.214	0.202	2.752	0.006
Psychological	Ethnicity	0.790	0.246	0.202	3.219	0.001
	Education	0.665	0.266	0.177	2.501	0.013
Social	Marital status	1.185	0.275	0.263	4.315	<0.001
	Occupation	-0.472	0.176	-0.165	-2.680	0.008
Environmental	Education	0.966	0.258	0.267	3.749	<0.001

Table 5 demonstrated the result of the final multiple linear regression model. Variable significantly associated with the physical domain of quality of life included: age was positively associated with QOL score with

each unit change would lead to a 0.59 unit increment in the QOL score. The psychological domain was significantly and positively associated with the ethnicity of parents/caretakers, *Brahmin/Chhetri* was

found to have 0.79 units more scores as compared to other ethnic groups. The psychological score was 0.67 units more among educated parents/caretakers as compared to those who were illiterate or had formal education. Similarly, variables significantly associated with the social relationship domain of quality of life included: marital status and occupation. The social relationship score increased by 1.19 units among married participants as compared to

others. Occupation (agriculture) was negatively associated with the QOL scores with each unit change would lead to a 0.47 unit reduction in the QOL score. The educational level of parents/caretakers was significantly and positively associated with the environmental domain of quality of life. The score of QOL was found to increase by 0.97 units among educated parents compared to those who are illiterate or had formal education.

Table 6 Quality Life of Parents having a child With Disability Depending on the Type of Disability Variable

Type of disability	Frequency	Physical Domain	Psychol. Domain	Social Domain	Environmental Domain
		Mean	Mean	Mean	Mean
Physical	140	13.50	12.83	15.61	12.10
Mental	15	13.83	12.18	16.09	12.13
Cognitive	22	13.87	12.48	14.91	11.82
Autism	10	13.66	12.00	16.00	11.70
Multiple	57	13.57	12.42	15.53	11.54
Total	244	13.58	12.63	15.57	11.93

Table 6 revealed that according to the Physical disability mean score of the physical domain was (13.5) and the environment was (12.10). Mental disability means the score was highest on the social domain (16.09) and lowest in environmental (12.13). Cognitive disability means the score was highest on the social domain (14.91) and lowest on the physical domain (13.87). The autism disability means the score was highest on the social domain (16.00) and lowest in the environmental domain (11.70). Multiple disabilities mean score was highest on the physical domain (13.57) and lowest on the environmental domain.

DISCUSSION

Socio- demographic characteristics showed that (63.6%) of the participants were in the age group of 31 to 50 years with age ranging from 14 to 84 years. The majority (64.3%) of the participants were *Janjati*, followed by 27% of *Brahmin/Chhetri* and 8.2% Dalit participants. More than one fourth (31.1%) of the participants were illiterate or had informal education. The mean scores for physical, psychological, social relationships and environmental domains are 13.6 (SD=1.4), 12.6 (SD=1.8), 15.6 (SD=1.3) and 11.9 (SD=1.7) respectively. The mean physical, psychological and environmental domains of quality of life is significant at $p < 0.05$ in the

different age group. In contrast to that, the social domain of quality of life is not significant. The mean Psychological domain of quality of life is significant at $p < 0.05$ level with different ethnic groups and not significant with other domain like physical, the social and environmental domain.

All four (physical, psychosocial, social and environmental) domains are significant at $p < 0.05$ level according to educational status. It can be concluded, education likely to determine the quality of life of parents who has children with disability. There is a positive correlation between physical, psychological and environmental. However, the physical domain is weakly correlated with the social domain. There is a moderate positive correlation between psychosocial social domains which is significant at the 0.05 level. However, the social and environmental domain is weakly correlated. According to types of disability, Physical disability means score highest on physical domain 13.5 mental disabilities mean score was highest on Social domain 16.09. Cognitive disability means the score was highest on the social domain that is 14.91. The autism disability means the score was highest on Social domain 16.00. Multiple disabilities mean score was highest on physical domain 13.57.

In the present study, the caregiver gained the highest scores on the social aspect 15.6

(SD=1.3) and lowest in the environmental 11.9 (SD=1.7) domain. In contrast with the present findings conducted in Iran among 70 parents having Down syndrome, children showed that the highest scores on the physical aspect.⁸ It may be due to the early identification of problems and appropriate intervention. Similarly, another study conducted in Saudi Arabia among families having children with disabilities (n=306) was also contrasted with the present findings where Environment domain had the highest score (SD=14.21) and the Spiritual domain had the lowest score (SD=4.72).⁹ It may be due to the quality of life of parents having a child with disability depending on the type of a disability variable. In the present study, the parents having a child with Cognitive disability mean score was highest on the social domain (14.91) and lowest on the physical domain (13.87) whereas autism disabilities mean score was highest on Social domain (16.00) and lowest in the environmental domain (11.70).

The study conducted in New Delhi, India with 60 parents having children of learning and autistic disability result findings contrasted with the present findings. Mothers of children with specific learning disabilities was a better quality of life in the physical domain and mother having children with autistic disorders were most likely experiencing poor quality of life in the physical domain.¹⁰ It may be due to different childhood conditions and their

different effect as a consequence that can interfere parents quality of life²⁰. In the present study, it has been found that the physical domain is weakly correlated with the social domain. There is a moderate positive correlation between psychosocial and social domains. However; the social and environmental domain is weakly correlated. It means a change in one domain from one value to the other domain will also change in its corresponding to change in the domain.

CONCLUSIONS

The Quality of life (QoL) of parents having children with disability was highest for social domain and lowest for environmental domain. The physical, psychosocial and environmental domain of QoL had statistically significant positive correlation. Likewise, age, ethnicity, marital status, education and occupation were found to have statistical significance with one

or more domains and were the predictors of QoL of the parents/caretakers having a child with a disability.

We recommend that health care and welfare professionals should focus in particular on people with a higher age group, disadvantaged and marginalized groups, illiterate, those who are unmarried, divorced or separated and those engaged in agriculture and carry out interventions aimed at improving their quality of life

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