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Quality of Life among Primary Caregivers of Children with Cerebral Palsy Living in Sarlahi and Rautahat Districts of Nepal

Bina Pandit,¹ Jitendra Kumar Singh,² Ananda Kumar Karn,³ Rina Pandit⁴¹Rehabilitation Science Department, Dhaka University, Bangladesh, ²Prerana Sarlahi, Nepal, ³Care Nepal, ⁴Health Care management, Pokhara University, Nepal.

ABSTRACT

Background: The objective of this study was to determine the quality of life and factors associated with quality of life among primary caregivers of children with Cerebral palsy.

Methods: A cross-sectional study was carried between primary caregivers of children with cerebral palsy in rehabilitation group and non-rehabilitation group. Purposive sampling technique was used to collect data

Results: Median age of caregivers was 34 years (age 20-70 years), and there was significant difference between age in two groups ($p=0.028$). 83 (86.5%) caregivers were female with significant difference between gender in rehabilitation and non-rehabilitation group ($p=0.03$). Majority of primary caregivers were mother 71 (74%) in both groups. Among all 96 caregivers, 78.1% of caregivers had poor quality of life (Score in questionnaire below 75% taken as poor quality of life). There was no significant difference between quality of life in rehabilitation and non-rehabilitation group ($p=0.42$). Factors associated with quality of life in rehabilitation groups was illiteracy ($p=0.005$), aggressive nature of child ($p=0.050$), uncooperative nature of child ($p=0.025$), poor knowledge about child condition ($p<0.001$), and low financial support ($p=0.051$). Similarly, factor associated with quality of life in non-rehabilitation group was gross motor function classification system level of child ($p<0.001$) and more perceived stress ($p=0.048$).

Conclusions: Majority of primary caregivers was mother and had poor quality of life and there was no significant difference between overall quality of life of caregivers in rehabilitation and non-rehabilitation group.

Keywords: Cerebral palsy; quality of life; primary caregivers

INTRODUCTION

Caring child with Cerebral palsy (CP) required more time from primary caregiver as well as more resources. The cost of providing care to a child with CP increases approximately 2.5-20 times.¹ The Quality of Life (QOL) of caregiver of children with CP is often not taken as the main focus by rehabilitation professional.² Therefore, till date, we do not know whether rehabilitation service has any effects on QOL of caregiver or not. When the child is affected, it affects whole the family and especially caregiver.³ Close presence and active participation of caregiver is required in all phase of management of children with CP.^{4,5} Therefore it is necessary to focus and determine overall QOL of caregiver along with the factors associated with QOL of Caregivers in Nepal. The objective of this study was to determine the QOL and

factors associated with QOL among primary caregivers of children with CP.

METHODS

A cross-sectional study was done to determine QOL of caregivers and factors associated with it from December, 2017 to May, 2018. There were two comparison groups: Rehabilitation group (caregiver of those children with CP who were getting continuous rehabilitation service) and non-Rehabilitation group (Caregiver of those children with CP who were identified by Prerana Rehabilitation center (PRC) but had not received rehabilitation service or discontinued rehabilitation service because of different undefined reason). Prerana Rehabilitation Center (PRC) is situated in Malangwa, Sarlahi district and provides service in 8 districts of Province-2 through-

Correspondence: Bina Pandit, Rehabilitation Science Department, Dhaka University Bangladesh, Email: panditbina@gmail.com, Phone: +9779819632154.

Institutional based service as well as outreaches service. More clients are serviced on out-reach based; due to lots of barrier, many people cannot access service from center. Children with CP in Rautahat district mainly served through community based service. From last few years, in Sarlahi there is no facility of community based service. Therefore, this study was done in these 2 districts through community visit.

Primary caregivers of those children who were diagnosed with CP and were receiving continuous rehabilitation service from rehabilitation center or had discontinued rehabilitation service and living in community of Sarlahi and Rautahat district of Nepal were included in the study. "Primary caregiver is the main care provider who spends most of the time in caring the child with CP and provides all the support that a child required including support in Activities of Daily Living (ADL)".

Sampling was carried through purposive sampling technique. As this study was carried out through the community visit, therefore I took 96 samples for this study, 56 respondents were in rehabilitation group and 40 respondents were in non-rehabilitation group. From the existing database of PRC, list of children with CP, their caregiver name, contact number, and address were drawn. Then a phone call was made to ensure the caregiver meet the inclusion criteria. The inclusion criteria of the study was Primary caregivers of children with CP; age of children was in between 4 -12 years, caregivers of those Children with CP who were register in database of PRC, Gross Motor Function Classification System (GMFCS) level II, III, IV, and V, Caregivers of children with CP who were willing to response in this study

Data was collected by using self-develop well-structured questionnaire. The questionnaire of QOL was developed by taking a reference from WHO-QOL BREF,⁶ Ferran and Power Quality of life index questionnaire,⁷ Quality of life questionnaire and also focusing on a living scenario of people in Nepal.

The questionnaire was divided into four parts and it took about 20-25 minutes to complete the entire questionnaire by each respondent. The first part of questionnaire consisted of demographic data of caregivers and children with CP. Second part of questionnaire consists, questions on all the factors associated with child problem. Third part of questionnaire consists, questions on all the factors associated with caregivers and Fourth part of questionnaire consists of questions on QOL of caregivers. In order to improve the quality of the study, first of all the questionnaire was translated into a National

language that is Nepali. The questionnaire was translated following the standard procedure of linguistic validation that is, In the first step all questionnaire was translated in to Nepali language by two Nepalese translators, In the second step, two Nepali version of questionnaires were reconciled and in the third step reconciled Nepali version of the questionnaire was translated in to English version questionnaire by the 3rd translator. The translated questionnaire was cross-checked and pilot study was carried out to ensure the validity of the questionnaire. After reviewing the results of pilot study, little changes were made in prepared questionnaires like in question 14 mixed type of CP was added and similarly in question 25, category 1- no barrier I am not sure actually therapy service improve child condition was added.

Firstly, data was entered in Microsoft Excel. Statistical Package for social science (SPSS) software version 16 was used for the data analysis. Data was re-coded as required. Reliability test on SPSS was done to ensure internal validity of the questionnaire. Descriptive analysis was done to calculate frequency and percentage by using custom table and it was presented in tables and figures. Comparison of demographic data and other variables of two groups were done using chi-square test. t test was used for comparison of QOL of rehabilitation and non-rehabilitation group.

RESULTS

Following the inclusion criteria, 96 primary caregivers were selected. Eight were excluded due to the exclusion criteria- five children had signs of puberty, one caregiver was unable to communicate, two caregivers were having another disable person at home.

Table 1 shows 56 (58.3%) primary caregivers of children with CP on rehabilitation group (who are under continue rehabilitation) and 40 (41.7%) primary caregiver of children with CP on non-rehabilitation group (Who have discontinue rehabilitation) were enrolled in the study. Age of respondents ranged from 20-70 years, as parents and grandparents both were included in this study.

Median age of caregivers in rehabilitation group was 32.50 years; Median age of caregivers in non-rehabilitation group was 35 years, and median age in both groups was 34 years.

Looking at the relationship of child with all 96 respondents, 71 (74%) were mother, 8 (8.3%) were father, 9 (9.4%) were grandmother and 8 (8.3%) were others. This shows maximum respondents were mother, as mother is taken as primary caregivers.

Out of 56 respondents- in rehabilitation group, 19 (33.9%) children were having Gross Motor Function Classification System (GMFCs) level II, 16 (28.6%) were having GMFCs level III, 19 (33.9%) were having GMFCs level IV and 2 (3.6%) were having GMFCs level V. In non-rehabilitation group out of 40, 19 (47.5%) children were having GMFCs level II, 5 (12.5%) were having GMFCs level III, 8 (20%) were having GMFCs level IV and 8 (20%) were having GMFCs level V. In both group, more children 38 (39.6%) are having GMFCs level II and less number of children are in GMFCs V that is 10 (10.4%) (Table 2). Out of 56 respondents- in rehabilitation group, most of child 20 (35.7%) were uncooperative in nature, 14 (25%) were friendly in nature, 12 (21.4%) were aggressive in nature, and only 10 (17.9%) were helpful in nature. In Non-rehabilitation group out of 40 children, 13 (32.5%) were aggressive in nature, 11 (27.5%) friendly in nature, 9 (22.5%) were helpful in nature and 7 (17.5%) uncooperative in nature (Table 2).

For caregiver of children with CP in rehabilitation group, mean score in Overall QOL was 80.05 ± 12.08 and for caregivers of children with CP in non-rehabilitation group mean score on over all QOL was 78.00 ± 12.45 . Statistically, there was no significant difference between overall QOL in rehabilitation group ($M=80.05$, $SD= 12.08$) and non-rehabilitation group ($M=78.00$, $SD= 12.45$)

condition; $t = 0.81$, $p=0.42$ (Table 3).

Assessing the association between education level of caregivers and QOL by chi-square in rehabilitation group, the obtain result was $\chi^2 (3, N=56) = 12.44$, $p=0.006$. This shows that, there was association between education level of caregivers and QOL of caregivers was significant in this study. Similarly result obtained on association between nature of child and QOL of caregivers in rehabilitation group was $\chi^2 (3, N=9=56) = 8.749$, $p=0.03$. Association between knowledge about child condition and QOL of caregivers the obtain result of test was $\chi^2 (1, N=56) = 14.94$, $p=0.001$. This shows there was significant relationship between knowledge about child condition and QOL of caregivers in the rehabilitation group. The calculated result for association between financial support and QOL of caregivers was $\chi^2 (2, N=56) = 6.25$, $p= 0.04$ (Table 4).

The result of chi-square tests for association between GMFCs and QOL of caregivers was $\chi^2 (3, N=40) = 16.77$, $p<0.001$ and the tests for association between perceived stress and QOL of caregivers was $\chi^2 (1, N=40) = 4.409$, $p= 0.03$. This shows there was association between GMFCs level and QOL, similarly perceived stress and QOL of primary caregivers found to be associated (Table 5).

Table 1. Frequency distribution and comparison of socio demographic data of caregivers in Rehabilitation and Non-rehabilitation group.

Level		Caregivers of children with CP in Rehabilitation Group (n=56)	Caregivers children with CP in Non-rehabilitation group (n=40)	Total (n=96)	p Value
Caregivers		n(%)	n (%)	n (%)	
District	Sarlahi	13 (23.2)	34 (85.0)	47 (49.0)	<.001
	Rautahat	43 (76.8)	6 (15.0)	53 (51.0)	
Age (in years)	20-30	25 (44.6)	15 (37.5)	40 (41.7)	0.028
	31-40	21 (37.5)	12 (30)	33 (34.4)	
	41-50	9 (16.1)	5 (12.5)	14 (14.6)	
	51+	1(1.8)	8 (20.0)	9 (9.4)	
Gender	Male	4 (7.1)	9 (22.5)	13 (13.5)	0.032
	Female	52 (92.9)	31 (77.5)	83 (86.5)	
Type Of Family	Small	32 (57.1)	19 (47.5)	51 (53.1)	0.234
	Joint	24 (42.9)	21 (52.5)	45 (46.9)	
Marital status	Married	52 (92.9)	37 (92.5)	89 (92.7)	0.941
	Widow	4 (7.1)	3 (7.5)	7 (7.3)	
Education	Illiterate	36 (64.3)	35 (87.5)	71 (74.0)	0.05
	Primary	8 (14.3)	3 (7.5)	11 (11.5)	
	Secondary	10 (7.9)	1 (2.5)	11 (11.4)	
	High school and above	2 (3.6)	1 (2.5)	3 (3.1)	

Occupation	Unemployment	2 (3.6)	5 (12.5)	7 (7.3)	0.192
	Housewife	36 (64.3)	26 (65.0)	62 (64.6)	
	Agriculture	12 (21.4)	8 (20.0)	20 (20.8)	
	Others	6 (10.7)	1 (2.5)	7 (7.3)	
Relation to children	Mother	44 (78.6)	27 (67.5)	71 (74.0)	0.46
	Father	3 (5.4)	5 (12.5)	8 (8.3)	
	Grandmother	4 (7.1)	5 (12.5)	9 (9.4)	
	Others	5 (8.9)	3 (7.5)	8 (8.3)	

Table 2. Characteristic of child.

Level		Caregivers of children with CP in Rehabilitation Group (n=56)	Caregivers children with CP in Non-rehabilitation group (n=40)	Total (n=96)	p Value
Children with CP		n(%)	n (%)	n (%)	
Type of CP	Spatic	51 (91.1)	28 (70.0)	79 (82.3)	.011
	Ataxic	3 (5.4)	2 (5)	5 (5.2)	
	Athetoid	2 (3.6)	4 (10)	6 (5.2)	
	Mixed	0 (0)	6 (15)	6 (5.2)	
GMFCS level	II	19 (33.9)	19 (47.5)	38 (39.6)	.009
	III	16 (28.6)	5 (12.5)	21 (21.9)	
	IV	19 (33.9)	8 (20.0)	27 (28.1)	
	V	2 (3.6)	8 (20.0)	10 (10.4)	
Nature of child	Aggressive	12 (21.4)	13 (32.5)	25 (26.0)	.24
	Uncooperative	20(35.7)	7 (17.5)	27 (28.1)	
	friendly	14 (25.0)	11(27.5)	25 (26.0)	
	Helpful within possibilities	10 (17.9)	9 (22.5)	19 (19.8)	
Health Condition of children	Other health problem	18 (32.1)	6 (15.0)	24 (25.0)	.05
	No other problem	38 (76.9)	34 (85.0)	72 (75.0)	
Participation of child	No participation	14 (25.0)	4 (35.0)	18 (29.2)	.28
	Participation	42 (57.0)	25 (65.0)	67 (70.8)	

Table 3. Quality of life of respondents.

Quality of life domain	Caregiver of children with CP in rehabilitation group Mean \pm SD	Caregiver of children with CP in Non-rehabilitation group. Mean \pm SD	P value
Health Domain	21.84 \pm 4.17	22.72 \pm 4.11	.30
Psychological	21.79 \pm 4.10	21.18 \pm 4.61	.49
Family Relationship	12.59 \pm 3.10	12.48 \pm 3.63	.86
Social participation	11.21 \pm 3.70	8.95 \pm 2.63	.001
Environmental	12.62 \pm 3.43	12.67 \pm 3.62	.94
Overall QOL	80.05 \pm 12.08	78.00 \pm 12.45	.42

Independent t test * Level of significance: $p < 0.05$

Table 4. Factors associated with QOL of caregivers in Rehabilitation Group.

Variable	Level	Quality of life of caregivers	
		Chi-square value	P value
Caregivers			
Age (in years)	20-30	6.517	0.089
	31-40		
	41-50		
	51+		
Gender	Male	0.150	0.699
	Female		
Type of Family	Small	0.041	0.840
	Joint		
Marital status	Married	0.936	0.333
	Widow		
Education	Illiterate	12.44	0.006*
	Primary		
	Secondary		
	High and above		
Children with CP Type of CP	Spastic	1.194	0.551
	Ataxic		
	Athetoid		
	Mixed		
GMFCs level	II	2.246	0.523
	III		
	IV		
	V		
Nature of child	Aggressive	8.749	0.033*
	Uncooperative		
	friendly		
Knowledge about Child condition	Helpful within possibilities	14.94	0.001*
	Poor Knowledge		
	Good Knowledge		
Financial support	No support	6.25	0.044*
	Moderate support		
	Full support		
Perceived stress	Always stressed	0.345	0.557
	Not stressed		

X² test, * Level of significance: p < 0.05

DISCUSSION

The purpose of this study was to determine the quality of life and factors associated with QOL among primary caregivers of children with CP living in Sarlahi and Rautahat districts of Nepal. This study shows majority of primary caregivers were young mothers. A study⁷ showed caregivers of children with CP relatively younger with mean age of 30 years and female were most involved as caregiver. A study⁸ results show that median age of primary caregivers was 33.6 years, and dominant young age people are less involved as primary caregiver, though they provide support and assistance in caring process. Similarly other study revealed that all other family members are involved in support caring, but mother is specially engaged as a primary caregiver of children with disabilities.⁹ The finding of this study also shows that, both the group had poor quality of life. Many study on QOL of primary caregivers shows that, QOL of caregivers is significantly lower than caregivers of normal child.^{10,11} Caring the child with disability throughout the day limits the social participation.¹¹ A study¹² showed that rehabilitation service does not significantly influence overall quality of life of caregivers, some improvement is seen only in pain domain of caregivers and GMFCS level of children with CP. In one study,¹³ it was mentioned that rehabilitation program is only focused in children with disabilities, it does not have any impact on quality of life of caregivers. Caregivers received enough support from their immediate family but are unhappy from the support they received from health professions.¹⁴ A study¹⁵ also reported that rehabilitation have no significant effect on the caregivers' psychological aspect. This study reported, majority of caregiver in non-rehabilitation group have poor QOL due to increase in severity of child condition. Level of disability in children was correlated with parental stress, which directly lowers QOL of caregivers.¹⁶ Primary caregivers of children with CP who had aggressive and uncooperative child have poor QOL than primary caregivers who had child helpful in nature in all possibilities. Aggressive and uncooperative behaviour was clearly associated with lower QOL and increased level of burden in caregivers.^{17,18}

The finding of this study shows, parents of children with severe disability experience higher level of stress. Rehabilitation is the cornerstone of treatment in CP, and for effective management parents cooperation is required. However, rehabilitation may place additional burdens on caregivers.¹⁵ Stress in caregiver was not associated with functioning of child but also associated with nature of family and social support.¹⁹

This study highlight active participation of caregivers is required while planning treatment protocol of children with CP. This study would be used by policy makers and rehabilitation professional to design treatment protocol focusing caregiver centered approach. There was some limitation in this study that was inability to randomly select primary caregivers. Inability to match the characteristic of caregivers in rehabilitation and non-rehabilitation group, both groups is not totally homogenous; majority of respondents in rehabilitation group were from Rautahat district, education level of caregivers was different were interviewed.

CONCLUSIONS

According to research objective, it was determined that majority of primary caregivers were mother and had poor QOL and there was no significant difference between QOL in of caregivers in Rehabilitation and Non-rehabilitation group. The major factors associated with poor QOL of caregivers of children with CP in rehabilitation group are education level of caregivers, nature of child, knowledge about child condition, financial supports. Similarly, severity of child disability and more perceived stress are most predominating factor that is associated with QOL of primary caregivers in children with CP in non-rehabilitation group. QOL of caregivers must be focused by rehabilitation professionals to achieve adequate functional outcome in children with CP as proper rehabilitation and habilitation of children with CP depends of care and support received from caregivers.

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