

Determinants of Health-related Quality of Life of Mothers having Children with Cerebral Palsy in Brahmanbaria PSOSK, Bangladesh

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Received on: May 8, 2021. Accepted on: November 15, 2021.

ABSTRACT

Children with cerebral palsy (CP) need more attention and care, especially from their mothers. This can affect the mothers' quality of life (QOL) adversely. This study sought to assess the health-related quality of life (HRQOL) of mothers of children with CP and their determine, especially those receiving treatment for their children at Brahmanbaria, PSOSK in Bangladesh. Using a convenient sampling method, 70 mothers with children aged 2-12 years with CP from the Brahmanbaria PSOSK were selected and enrolled in a cross-sectional study. Mothers' mean age \pm standard deviation was 29.79 ± 4.02 years. The maximum child had spastic type of CP (68%). It is found that family income, type of family, living with husband, number of children and children age had significant influence ($p < .05$) on the HRQOL of mothers for certain domains. In addition, caring for a child with CP had significantly influenced on the HRQOL of the mothers, irrespective of their socio-economic status. Measures to improve quality of life and health of mothers of children with cerebral palsy should be incorporated in the management of CP with emphasis on identified areas of need.

Keywords: Health, Quality of Life, Cerebral Palsy, Determinants

INTRODUCTION

To measure health status in health and medical research, researchers often use a recognized tool called Health Related Quality of Life (HRQOL) (Habashneh et al., 2012). The identification of factors that influence HRQOL may provide indications for arranging proper treatment, care, and rehabilitation programs (Soh et al., 2013). It is reported that every country wants to improve its citizens HRQOL and well-being as the principal agendas of the country (Prudente et al., 2010). HRQOL is a subjective concept that encompasses all conditions and aspects of human life (Ahmadizadeh et al. 2015). HRQOL can be defined as the individual's perception of his/her position in life in the context of his/her culture and value systems in which he/ she lives, and in relation to his/her goals, expectations, standards, and concerns (Susniene & Jurkauskas, 2009).

Cerebral palsy (CP) is a common cause of childhood disability that shows a life-long partial or complete difficulties in movement, speech, comprehension, learning, and intellectual and emotional responses (Hasan & Islam, 2020). CP is one of the most common disorders of childhood (Gans, 1998) with an incidence of 2 to 3 per 1,000 live births (CDC, 2019). Earlier authors state that these impairments may compel the affected children to be dependent on others for doing their daily activities (Davis et al., 2010; Kaya et al., 2010). The effects of disability extend from the affected child to family members (Gardiner & Iarocci, 2012; Terra et al., 2011) who often is the child's mother or father because they (affected children) require special care (Karande & Kulkarni, 2009). Of the parents, mothers are more affected than fathers (Oh & Lee, 2009; Ones et al., 2005). This is because mothers play the primary role in raising children with or without disability in most cultures of the world (Ones et al., 2005) including Bangladesh.

Evidence suggests that the mother of a disabled child suffers from more physical and mental complications than the mother of a healthy child (Laurvick et al., 2006). Since a caregiver's HRQOL is related to physical health, mental health, social networks, and support and family dynamics (Krause, 2002), continuous care to meet the child's medical, physical and social needs can have a negative impact on it (Fatudimu et al., 2013).

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Cite as: Ahmed, K. J., Debnath, S., Alam, A., Bhattacharjee, I., & Hasan, M. (2021). Determinants of Health-related Quality of Life of Mothers having Children with Cerebral Palsy in Brahmanbaria PSOSK, Bangladesh. *Journal of Disability Studies*, 7(2), 84-89.

©IS Publications ISSN: 2454-6623 <http://pubs.iscience.in/jds>



A study reported that depression is very common among mothers with CP children and it has a negative impact on the mothers HRQOL (Diwan et al., 2011). In addition, the deterioration of mental health in mothers with CP children gives rise to experiencing physical complications such as low back pain to mothers, leading to more deterioration in HRQOL (Kaya et al., 2010). Caring for a person with disability can also affect a family's financial situation, as the presence of a person with disability can result in a large financial burden on families (Davis et al., 2010). Another factor that can be a source of worsening HRQOL in mothers having children with disabilities is that having a disabled child leads to social isolation of the family (Gorter et al., 2009). Similarly, a study shows that disability in children was reported to decrease social activities of mothers and to have an influence on routine deterioration (Keller & Honig, 2004).

Several studies have examined the HRQOL of caregivers of children with cerebral palsy in different parts of the world (Fatudimu et al., 2013; Glennet. al., 2009; Poley et al., 2012; Yilmaz et al., 2013) but the HRQOL of mothers of children with cerebral palsy in Bangladesh have not been investigated yet. Therefore, this study tried to generate evidence based information and make an attempt to understand the health-related quality of life of mothers having children with cerebral palsy in order to provide insights of the associated factors of quality of life of mothers of cerebral palsy children in the context of Bangladesh. Thus, this study sought to generate evidence-based information about the health related quality of life of mothers of children with cerebral palsy in the context of Bangladesh and to understand the factors that affect their HRQOL.

METHODOLOGY

This descriptive cross-sectional study was conducted among 70 conveniently selected mothers of children with cerebral palsy from August to December 2019 who came to seek health care for their children in the Department of Physiotherapy and Rehabilitation at the Brahmanbaria Protibondhi Sheba-o-Sahajjo Kendra (PSOSK). Mothers who had no children with disabilities other than CP between the ages of 2 and 12, were with the CP child in the same home, and only sought outpatient services for children with CP, were included in the study. On the other hand, mothers who smoked, pregnant and were reluctant to take part in the study, and had a previous history of mental illness or a chronic medical condition before or after childbirth of CP and who cared for the elderly or mentally or physically disabled and whose CP children showed signs of puberty were excluded from this study.

Data were collected through face-to-face interviews using a structured questionnaire comprised of a Short Form Health Survey-36. This questionnaire had two parts. The first part again divided into two sub-categories. The first subdivision was designed to collect information on mothers' socio-demographic profiles, history of habits and medications. Details of the cerebral palsy child were collected from the second sub-section

of this part such as age, etiology of the disease, type of disease, use of assistive devices, type of paralysis, presence of skeletal and intellectual deformities. The second part of this questionnaire contained the Short Form Health Survey (SF)-36. SF-36 is a valid and frequently used scale to evaluate HRQOL, specific for no groups of age, disorder, and treatment, includes general health concepts, and composed of 36 questions with 8 subscales as physical function, physical role limitation, emotional role limitation, bodily pain, social function, mental health, vitality, and general health. Scores of items are encoded for each subscale and formed as a scale ranging from 0 (poorest health status) to 100 (best health status). SF-36 has two summary measures as physical component scale (PCS) and mental component scale (MCS). PCS is comprised of subscales of physical function, physical role, bodily pain, and general health, and MCS is comprised of subscales of vitality, social function, emotional role, and mental health (Ware Jr, 2000; Ware Jr et al., 1995). The grading scale is based on percentages, thus scores close to 100% indicate a higher HRQOL. In the next step, participants were divided into two groups based on achieving a total score of 70% in HRQOL, hence people who had a minimum score of 70% was categorized as having better HRQOL, and the rest were put in a group with worse HRQOL (Ahmadzadeh et al., 2015). In order to ensure error free, validated and credible data, the whole procedure was done by the first author who is a graduate physiotherapist.

After completion of data collection, each question was checked thoroughly for consistency and completeness. Data were cleaned and edited before analysis. Data was then entered into SPSS Version 22 software for analysis. Descriptive statistics of frequency, percentage, means, medians, mode, standard deviation, tables and graphs were used to summarize the data. Inferential statistics were used to observe the association between the variables. P-value < 0.05 was considered as significant.

Prior to data collection, necessary permission was obtained in written and oral format from the participants and the study place authorities. In addition, the questionnaire was translated into Bengali version for the convenience of study participants, and for obtaining error-free data

RESULTS

Table 1 shows that a maximum of 54.3% (38) of participants were in the 20-30 years age group and about 80% (56) of them were Muslim. Housewife was mentioned as the occupation by the highest 82.85% (58) of participants and most 64.3% (45) of them lived in rural areas. Primary education was marked as their highest educational qualification by the highest number of participants 41.4% (29). The maximum 41.4% (29) had a monthly family income of 10,000-30,000 Bangladeshi Taka. The utmost 61.4% (43) of participants lived in the extended family and the highest 82.9 % (58) of them lived with their husband. In terms of the number of children, the highest 48.6% (34) of participants had 2 children. Tobacco was identified as the current habit with a maximum of 30% (43) of participants and the most 94.3% (66) of respondents were not on taking medication.

Table 1. Socio-demographic profile and habitual & medication history (n = 70)

Variable	Category	Frequency	Percentage
Age in years	20-30	38	54.3
	>30	32	45.7
	Mean \pm SD	29.79 \pm 4.02	
Religious Status	Muslim	56	80.0
	Hindu	13	18.6
	Buddhist	1	1.4
Occupation	Housewife	58	82.85
	Service holder	9	12.85
	Retired and Business	3	4.28
Habitat	Urban	17	24.3
	Semi-urban	8	11.4
	Rural	45	64.3
Educational Status	Illiterate	22	31.4
	Primary	29	41.4
	Secondary/diploma	12	17.1
	Degree/bachelor/honors	6	8.6
	Masters or others	1	1.4
Family monthly income	<10,000tk	16	22.9
	10,000-30,000tk	29	41.4
	>30,000tk	25	35.7
Type of Family	Core/nuclear family	43	61.4
	Combined Family	27	38.6
Living with husband	Yes	58	82.9
	No	12	17.1
Number of children	1	9	12.9
	2	34	48.6
	>3	27	38.6
Current habit (Yes)	Smoking	14	10
	Alcohol	2	1.4
	Tobacco	43	30
	Regular exercise	0	0
On Medication	Yes	4	5.7
	No	66	94.3

Table 2 illustrates that 54 (77.1%) of children with cerebral palsy were in the 2-6 years age group and 16 (22.9%) were in the 7-12 years age group. In the case of gender, males were 33 (47.1%) and females were 37 (52.9%). In regards to etiology of the disease, most of the respondents replied that the principal etiology of their child's illness was peri-natal (n=63, 90%). Post-natal was indicated by the rest of the respondents (n=7, 10%) as the etiology of disease. During the survey, it was found that children were suffering from three types of cerebral palsy. Of these children, most 48 (68%) children were affected with spastic cerebral palsy. In addition, 16 (23%) and 6 (9%) children were suffered by ataxic and dyskinetic cerebral palsy, respectively. In this study, children with spastic, ataxic and dyskinetic cerebral palsy showed intellectual deformity. Children with spastic cerebral palsy (40 out of 70) are more likely to portray intellectual deformity than ataxic (16 out of 70) and dyskinetic (5 out of 70) variants. On the other hand, skeletal deformity was only observed in 3 children with spastic cerebral palsy. Around 21.4% of the respondents replied that they have

assistive device which is used as one of the treatment modalities for their child (n = 15, 21.4 %). In contrast, about 78.6 % noted that they do not depend on using assistive device as one of the treatment methods.

Table 2. Distribution of children with cerebral palsy based on age, etiology, type of disease, use of assistive devices and presence of skeletal and intellectual deformities (n = 70)

Variable	Category	Frequency	Percentage
Age in years	2-6	54	77.1
	7-12	16	22.9
Gender	Male	33	47.1
	Female	37	52.9
Disease etiology	Peri-natal	63	90.0
	Post-natal	7	10.0
Cerebral palsy type	Spastic	48	68
	Dyskinetic	6	9
	Ataxic	16	23
Presence of skeletal deformity	Spastic	3	4.2
	Dyskinetic	0	0
	Ataxic	0	0
Presence of intellectual deformity	Spastic	40	57.1
	Dyskinetic	5	7.1
	Ataxic	16	22.8
Use of assistive device	Yes	15	21.4
	No	55	78.6

Table 3. Health Related Quality of Life of Mothers Having Children with Cerebral Palsy

HRQOL Domain	Mean \pm SD
Physical functioning	64.83 \pm 21.87
Role limitations because of physical health problems	41.75 \pm 37.76
Role limitations because of emotional problems	45.61 \pm 37.45
Vitality (energy/fatigue)	55.45 \pm 79.93
General mental health (psychological distress and psychological well-being)	60.08 \pm 16.97
Social functioning	53.96 \pm 21.46
Bodily pain	58.57 \pm 25.98
General health perceptions	51.14 \pm 18.50
Total scale score	55.31 \pm 16.39

Based on the data shown in Table 3, it has shown the different mean \pm standard deviation of quality of life score among mothers having children with CP. The total mean score was 55.31 \pm 16.39. It has also shown the mean score in the different domains of quality of life among mothers.

Table 4. Association between Participants' Socio-Demographic Profile, and Habitual and Medication History, Children Age and Health-Related Quality of Life

Variables		Physical functioning	Role limitations because of physical health problems	Role limitations because of emotional problems	Vitality (energy/fatigue)	General mental health (psychological distress and psychological well-being)	Social functioning	Bodily pain	General health perceptions
Occupation	Mean	63.62	42.59	40.29	52.33	65.44	53.15	55.53	51.56
	P value	0.97	0.91	0.56	0.87	1.09	0.76	0.54	1.56
Educational status	Mean	62.43	40.21	41.98	54.76	61.915	53.35	55.42	51.23
	P value	0.89	0.99	0.66	0.78	1.22	0.89	0.45	1.56
Family income	Mean	64.52	43.19	40.19	52.60	65.97	53.91	55.51	50.23
	P value	0.09	0.11	0.03*	0.04*	0.01*	0.001*	0.54	0.29
Family type	Mean	64.72	42.725	40.76	52.78	65.835	52.72	54.445	51.79
	P value	0.04*	0.11	0.02*	0.01*	0.003*	0.006*	0.69	0.03*
Age	Mean	61.23	41.46	40.32	53.78	62.35	52.35	55.46	50.12
	P value	.89	.45	.76	.83	.79	.54	.67	1.76
Children age	Mean	62.34	42.33	41.23	52.34	64.46	53.23	53.23	51.12
	P value	.03*	.021*	.043*	.023*	.089	.097	.79	.001*
Number of children	Mean	61.29	43.34	40.45	51.23	64.45	53.23	55.56	50.45
	P value	.022*	.45	.53	.011*	.77	.83	.87	.92
Living with husband	Mean	63.71	42.72	41.26	52.23	64.93	51.92	54.87	51.67
	P value	0.03*	0.34	0.03*	0.01*	0.04*	0.006*	0.78	0.01*
Habitat	Mean	63.59	42.23	40.11	52.24	64.56	52.31	55.23	51.01
	P value	0.89	0.67	0.78	0.86	1.89	.67	.58	.73
Current habit	Mean	61.89	43.78	40.98	51.35	64.46	53.11	55.34	50.12
	P value	1.89	0.78	0.74	0.99	.76	0.99	0.48	.39
Medication	Mean	63.23	42.99	41.19	52.12	65.09	53.12	55.12	51.23
	P value	1.78	0.37	0.78	0.90	.78	.47	.76	.92
Religious status	Mean	64.12	43.23	40.20	52.12	64.97	53.01	55.51	50.89
	P value	.76	0.69	.66	.83	.75	.46	1.58	.39

The association between participants' socio-demographic status, and habitual and medication history, children's age, and health-related quality of life can be noticed from Table 4. It has been noticed that occupational status, educational status, participants' age, living area, current habit, medication and religious status do not have any influence on health related quality of life of mothers of children with CP because no domains' p-value has been found to lower than .05 in Table 4. On the other hand, it can be said that HRQOL has a significant association with family income, family type, children age, number of children, and living with husband since the p-value for some of the domains of HRQL has been found to less than .05.

DISCUSSION

This descriptive cross-sectional study was conducted to understand the health related quality of life of mothers of children with CP at the department of physiotherapy and rehabilitation center of Brahmanbaria PSOSK, Bangladesh. In order to accomplish the study aim, 70 mothers of children with CP were selected conveniently and a face-to-face interview was conducted by a structured questionnaire comprised of a Short Form Health Survey (SF)-36.

Caring for a child puts a lot of pressure on the mother. For mothers of children with disabilities, it is a thousand times bigger. In the search engine, limited studies examining the health-related quality of life (HRQOL) in mothers of children with CP were found. However, evidences suggest that both psychological and physical complications are faced by the mothers having children with cerebral palsy (Mobarak et al., 2000; Brehaut et al., 2004). In addition, this study shows that all domains of the HRQOL (sleep, energy, emotional response, social isolation, physical activity, and pain) were presented negatively in mothers of children with CP, which confirms that health-related quality of life measures physical, functional, psychological and social wellbeing (Ware Jr, 2003).

A full-time job can limit the caring role of a mother because she has to stick to her professional task for a large part of the day. Earlier an author reported a strong association between full time job and HRQOL of mothers of children with CP (Ahmadzadeh et al., 2015). In contrast, the present study found no relationship between these two variables, as it is assumed that 82.85% of the participants were housewives. Regarding the educational status, some literature (Yilmaz et al., 2013) has

found that it has no effect on the HRQOL of mothers of CP children while some other studies (Ones et al., 2005; Lawako & Soares, 2003) have found a strong effect of education on the HRQOL of mothers. However, the current research did not find any association between educational level and HRQOL as evidence suggest that ability to cope with stress and optimism about life may be more related to individuals' inherent traits and dispositions rather than educational status (Adegoke et al., 2014).

Bangladeshi culture is known for its characteristics of family bonding. In this research, it has been noticed that HRQOL of mother of children with cerebral has significant relationship to the type of family and living with husband. This is probably because of existing extended family system of Bangladeshi culture. In an extended family, mothers of children with CP receive physical and emotional support from the other family members which helps them devote more time to their special care needs child and reduce emotional stress. The more physical and emotional support, the less likely HRQOL is to be impaired. On the other hand, family income influences some aspects of the health-related quality of mothers according to the finding of this study. It is reported that the presence of child with CP impose a huge financial burden on a family (Davis et al. 2010). Having a sense of enough money to support children with disabilities' needs provides sound psychological assistance for which mothers may perform normal activities. This study focused solely on the presence of socioeconomic involvement on the health-related quality of mothers of youngsters with CP; it is not the depth of involvement that can be considered as a limitation of this study.

The responsibility of a person is increased in accordance with the age. It increases even more if someone is looking after a disabled person. A disabled child needs more time and labor than a normal child. Time and labor levels increase as the child grows older. The child's physical structure, emotional needs and medical condition are largely responsible for this. As a result, mothers sacrifice their own time, social activities, and career in order to look after their children perfectly. According to this research finding, it is transparent that child age has a reverse influence on health related quality of mother of children with CP. As opposed to, this study did not find any influence of mothers' age on HRQOL unlike previous study (Ahmadizadeh et al., 2015). A small size sample could be the reason for this result. Hence, a study with numerous samples is recommended to carry out in this regard. Furthermore, the running study found a relationship between mothers' child quantity and HRQOL. A population based survey states that the more children a woman has the fewer resources that could be allocated to her (Wu & Li, 2012). This can force mothers to put more pressure on them to perform tasks that can affect their physical, emotional, social and economic lives. Prior author reports that parents with multiple disabled children are at greater risk of stress because of the amount of care they provide for their children (Hong et al., 2008).

In the search engine, this study did not find any literature regarding the relationship between the mothers' HRQOL and their habitat, current habit, medication, and religious status. It is suggested to consider it as the limitation of this study. On the other hand, it is requested to carry out a depth study about this as the current statistics did not also find any association between the mothers' HRQOL and their habitat, current habit, medication, and religious status.

In light of the literature and the study findings, HRQOL of mothers with CP children is considered to be affected because of their children. Therefore, in planning a rehabilitation program for CP children, HRQOL of mothers should also be evaluated in detail, as well as that of CP children, and as to problems defined, solutions should be produced. Additionally, mothers should be encouraged to take part in social activities related to their interests, and those with depressive symptoms should be supported psychologically. Therefore, it is considered that mothers, undertaking the most significant role in the rehabilitation and caring for the child, should be interested in CP children in a better way.

CONCLUSION

Based on the results of this study, it is transparent that there is a relationship between HRQOL of mothers and having a CP child. Caring for a child with CP significantly impacted on the HRQOL of the mothers, irrespective of their socio-economic status. Measures to improve quality of life and health of mothers of children with cerebral palsy should be incorporated in the management of CP with emphasis on identified areas of need. It is also recommended to increase mothers' HRQOL, and mothers of children with CP should be motivated to join social activities related to their interests, and mothers with depressive symptoms should be psychologically supported.

LIMITATION

A major limitation of the present study is that the subjects were all from a clinic population. Thus, the findings may not generalize to the entire population of CP patients seeking treatment, because their socio-economic levels may not match precisely. The small sample size is another possible limitation. Because all the 1st-time applicants to the center were included in this study, it is believed that the study group is a representative sample of Bangladeshi CP patients. Nevertheless, the small sample size restricts the ability to perform multivariate analysis and thereby assess interactions among variables. Thus, only the main effects of variable interactions have been analyzed. The small sample size may constitute a limitation as to the generalizability of findings from this study, thus the findings need to be interpreted with caution. Another possible limitation may arise from the fact that the study did not explore the relationship or influence of variables such as social support, severity of disability which had been reported to affect quality of life. However, the absence of a child without disability in the control group may make assessment of some of these variables among them unrealistic.

ACKNOWLEDGMENTS

The authors would like to express their gratitude to the authority of School of Science and Technology, Bangladesh Open University, and to the management of Protinodhi Sheba-o-Sahajjo Kendra, Brahmanbaria, Bangladesh for the assistance they provided during the research.

Conflict of Interest: None

Source of funding: None

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