

# Comparison of Quality of Life of Caregivers of Children with and without Disabilities

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## ABSTRACT

**Introduction:** Taking care of a child with disability not only affects the health of the caregiver but also has a detrimental effect on their quality of life. Presently health providers are focussing on the child with disability, their caregivers are ignored to a large extent.

**Aim:** To compare the quality of life of the caregivers of children with or without disabilities.

**Materials and Methods:** A cross sectional study was conducted in the outpatient department of Physical Medicine and Rehabilitation, Lady Hardinge Medical College and associated Kalawati Saran Children's Hospital, New Delhi from November 2011 to October 2012 with prior approval from the Institutional Ethics Committee. After obtaining informed consent, a total of 400 participants (200 each in case and control group) who satisfied the inclusion criteria were included in the

study. A pre-structured proforma containing the demographic details of the family and WHOQoL-BREF questionnaire to assess quality of life of caregivers was filled. Statistical analysis was done using Statistical Package for Social Sciences (SPSS) version 21.0.

**Results:** In the present study it was observed that quality of life of caregivers of children with disabilities had statistically significant lower scores in all domains using WHOQoL-BREF scale as compared to control group.

**Conclusion:** Protocols should be framed in departments managing children with disabilities to address the health issues of the caregivers. Help in the form of regular counselling, peer group interaction within the hospital and respective local communities, support including respite care services are few things that can be incorporated in order to improve their quality of life.

**Keywords:** Disabled child, Environment domain, Physical health, Psychological health

## INTRODUCTION

According to World Health Organisation (WHO), Quality of Life (WHO-QoL) is defined 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. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment [1]. Parenting a disabled child requires lot of efforts and resources. This increase in demand has an implication on health of the parent caring for their child [2,3]. Many studies have been conducted to quantify the quality of life of caregivers of patients with chronic ailments like asthma [4], epilepsy [5], stroke [6], renal diseases on dialysis [7] etc. On the other hand very few studies have been done addressing the issue of quality of life in caregivers of children with disability. Brehaut JC et al., compared the health of primary caregivers of cerebral palsy children with other Canadian caregivers and found distress, chronicity of distress, physical, emotional and cognitive problems among caregivers of cerebral palsy children [2]. Raina P et al., reported that, higher the level of behaviour problems in a child with cerebral palsy, greater was the deterioration in psychological and physical health of the caregivers compared to caregivers of children with cerebral palsy with lower degrees of behaviour problems [3]. Quality of Life (QoL) of caregivers of children & adolescent with intellectual disabilities using WHO-QoL was done by Lin JD et al., and it was observed that mean scores of all 4 domains of WHOQoL-BREF were lower than the general population. Psychological well-being was the lowest satisfactory domain [8]. Chakraborti B et al., by using Short form-12 version 2 questionnaire found that parents of developmentally disabled children had significantly higher stress levels and mental health related quality of life compared to parents of children without disabilities [9]. Similar study was done for caregivers of Lennox Gastaut Syndrome (LGS) using Short Form-36 and Hospital Anxiety

Depression Scale. Restricted social life, strained marital relations, difficulty in attending social events, reduced time for recreational activities and taking care of their own appearances were major problems found by the caregivers of these children. Anxiety was more prevalent than depression in caregivers of these children. They were experiencing social stigma and therefore lack of social support [10]. Kim KR et al., studied the burden on caregivers of patients of mitochondrial diseases associated with chronic disabilities using Zarit Burden Inventory, Medical Outcomes SF-36, Short version of WHOQoL and Beck Depression Inventory & Beck Anxiety Inventory.

Higher care giving burden, reduced SF36 scores, decreased WHOQoL-BREF scores and greater depression and anxiety were reported by the authors [11]. All the above studies were done in caregivers of children with a particular disease or disorder but Murphy NA et al., studied health of caregivers of children with disabilities. They found caregivers were in stress, poor physical health, worrying for the future and exhausted due to lack of respite services or social support [12]. Majority of studies done so far are from outside India. Few studies have been done in India with more focus on intellectual disabilities. Therefore, a study was planned to evaluate and compare the quality of life of caregivers of children with and without disabilities and to highlight the need to focus on health of their caregivers.

## MATERIALS AND METHODS

A cross sectional observational study was conducted in the Department of Physical Medicine and Rehabilitation, Lady Hardinge Medical College and associated Kalawati Saran Children's Hospital from November 2011 to October 2012 after approval from Institutional Ethics Committee (Number IEC-96/2011).

Caregivers of children with and without disabilities, who satisfied the inclusion criteria (Caregiver of child more than three-year-old and having only one child with disability) and exclusion criteria

(caregivers with any disease affecting their quality of life) and gave their informed consent, were included in the study.

Sample size calculation: Taking the values from the study of Manee F et al., as reference [13], the minimum required sample size with 99% power of study and 1% level of significance was 39 patients in each study group. To reduce margin of error, total sample size taken was 400 (200 caregivers per group).

A prestructured proforma addressing details about the participant's demographic profile like age of the child and their caregivers, gender of the child, type of caregiver (Mother, father or other), type of family, education of caregiver, area of living i.e., urban or rural, etc and WHOQoL-BREF (was used after attaining permission, but due to limited space the whole questionnaire has not been included in the article) was filled by the interviewer. WHOQoL-BREF is a cross culturally comparable quality of life measure which was developed collaboratively and field-tested across a number of cultural contexts. It assesses quality of life within six different domains. It is the short version of the WHOQoL 100 and is recommended for use when time is restricted or the burden on the respondent needs to be minimised. This scale contains 26 items and addresses 4 QoL domains: physical health (7 items), psychological health (6 items), social relationships (3 items) and environment (8 items). Two other items measure overall QoL and general health of the participants. Items are rated on a 5-point scale (low score of 1 to high score of 5) to determine a raw item score. Subsequently, the mean score for each domain is calculated, resulting in a mean score per domain that is between 4 and 20 [14].

## STATISTICAL ANALYSIS

Categorical variables were presented in number and percentage (%) and continuous variables as median. Normality of data was tested by Kolmogorov-Smirnov test. Wherever normality was rejected, non parametric test was used. Quantitative variables were compared using Mann-Whitney Test (as the data sets were not normally distributed) between the two groups. A p-value of <0.05 was considered statistically significant. The data was entered in MS EXCEL spreadsheet and analysis was done using SPSS version 21.0.

## RESULTS

Out of 400 caregivers evaluated, majority of the children were in the age group 3-7 years, whereas caregivers were in the age group of 25-35 years. In both groups there was a preponderance of female child. Mother more commonly accompanied the child to the outpatient department as compared to father. More children were residing in nuclear families as compared to joint families in both case and control group. Majority of caregivers belonged to urban areas with their level of education varying from illiteracy to secondary (class X). [Table/Fig-1].

Cerebral palsy was the most common cause of disability (78.5 %) followed by Mental retardation (6.5%). Children with other disabilities were very few between 1 to 5 and thus intergroup analysis could not be done [Table/Fig-2]. Quality of life score was significantly lower in case group as compared to control group in all domains of WHOQoL-BREF [Table/Fig-3]. Quality of life scores in all the

	Demographic features	Case group (200)	Control group (200)
Age group (Child)	3-7 Years	159 (79.5%)	153 (76.5%)
	>7-11 Years	35 (17.5%)	30 (15%)
	>11 Years	6 (3%)	17 (8.5%)
Age group (Caregivers)	15-25 Years	45 (22.5%)	48 (24%)
	>25-35 Years	120 (60%)	121 (60.5%)
	>35 Years	35 (17.5%)	31 (15.5%)
Gender (Child)	Male	69 (34.5%)	72 (36%)
	Female	131 (65.5%)	128 (64%)
Caregiver	Mother	171 (85.5%)	169 (84.5%)
	Father	23 (11.5%)	29 (14.5%)
	Other	6 (3%)	2 (1%)
Family	Joint	93 (46.5%)	97 (48.5%)
	Nuclear	107 (53.5%)	103 (51.5%)
Location	Rural	43 (21.5%)	25 (12.5%)
	Urban	157 (78.5%)	175 (87.5%)

[Table/Fig-1]: Demographic profile.

Sl. No.	Diagnosis	Number	Percent (%)
1.	Cerebral palsy	157	78.5
2.	Mental retardation	13	6.5
3.	Seizure disorder	5	2.5
4.	Duchenne's muscular dystrophy	4	2
5.	Post tubercular meningitic sequelae	3	1.5
6.	Spinal muscular atrophy	2	1
7.	Post encephalitic sequelae	2	1
8.	Autism spectrum disorder	2	1
9.	Meningomyelocoele	2	1
10.	Hearing and speech impairment	2	1
11.	Down's syndrome	2	1
12.	Post polio residual paralysis	1	0.5
13.	EhlerDanlos syndrome	1	0.5
14.	Hemophilic Arthropathy	1	0.5
15.	Acute infantile hemiplegia	1	0.5
16.	Arthrogryposis multiplex congenita	1	0.5
17.	Cong. Hypothyroidism with post-traumatic hemiplegia	1	0.5
	Total	200	100

[Table/Fig-2]: Diagnosis of children with disabilities.

	Case (200)	Control (200)	p-value
QOL	3	4	<0.001
Health	4	4	<0.001
Domain 1	15	16	<0.001
Domain 2	13	15	<0.001
Domain 3	16	16	0.001
Domain 4	13	15	<0.001

[Table/Fig-3]: WHOQoL-BREF scores.

	3-7 years children age group			8-11 years age group			>11 years age group		
	Case (159)	Control (153)	p-value	Case (35)	Control (30)	p-value	Case (6)	Control (17)	p-value
QOL	3	4	<0.001	3	4	0.004	3.5	3	0.577
Health	4	4	<0.001	3	3.5	0.159	4	3	0.636
Domain 1	15	16	<0.001	14	14.5	0.123	15	16	0.411
Domain 2	13	15	<0.001	12	15	0.006	15	15	0.694
Domain 3	16	16	0.001	16	16	0.497	14	16	0.169
Domain 4	13	16	<0.001	13	15	0.001	14.5	14	0.869

[Table/Fig-4]: Comparison of WHOQoL-BREF score in relation to child's age.

	15-25 years			>25-35 years			>35 years		
	Case (45)	Control (48)	p-value	Case (120)	Control (121)	p-value	Case (35)	Control (31)	p-value
QOL	3	4	0.003	3	4	<0.001	3	4	0.014
Health	3	4	0.015	4	4	0.004	4	4	0.081
Domain 1	14	16	0.018	15	16	<0.001	14	15	0.072
Domain 2	12	15	0.001	13	16	<0.001	13	15	0.002
Domain 3	15	16	0.188	16	16	0.006	15	16	0.131
Domain 4	13	15	0.01	13	16	<0.001	13	15	0.04

**[Table/Fig-5]:** Comparison of WHOQoL-BREF score in relation to caregiver's age.

	Mother			Father			Other		
	Case (171)	Control (169)	p-value	Case (23)	Control (29)	p-value	Case (6)	Control (2)	p-value
QOL	3	4	0.025	3	4	<0.001	3	4	0.388
Health	3	4	0.055	4	4	0.004	2.5	4	0.32
Domain 1	15	16	0.008	15	17	<0.001	14.5	15	0.696
Domain 2	13	15	0.001	13	15	<0.001	12.5	15	0.43
Domain 3	16	16	0.032	15	16	0.006	15.5	16.5	1
Domain 4	13	15	0.003	13	16	<0.001	12.5	15.5	0.558

**[Table/Fig-6]:** Comparison of WHOQoL-BREF score in various caregivers.

domains improved with increasing age of the child. After attaining the age of 11 years and above, scores obtained by the caregivers in both the groups were comparable [Table/Fig-4]. Caregivers in case group with age either less than 25 years or more than 35 years had better quality of life scores when compared to caregiver of children between 25 to 35 years in all domain except domain 2 and domain 1 within 15-25 years [Table/Fig-5].

We did not observe any correlation between low scores obtained in the questionnaire and gender of the child. The lower score was statistically significant ( $p$ -value  $<0.05$ ) in all the domains with respect to father belonging to the case group. Interestingly, mothers of case group were satisfied in the social relationship domain but the scores of other three domains were significantly low from mothers of children without disabilities. Even they rated overall Health and Quality of life better than fathers of disabled children [Table/Fig-6]. A higher quality of life score was observed in caregivers living in a joint family rather than in nuclear family setting. The better score achieved was mainly through the scores achieved in domain 4. Lower scores were seen in case group compared to the control group especially in caregivers residing in rural area vs caregivers of case group residing in urban area.

## DISCUSSION

Upbringing of a disabled child adds up to additional commitments by the caregivers emotionally, mentally, physically as well as socially. This secondarily leads to deterioration not only in the health of these parents but also on their quality of life. Present study has highlighted the fact that caregivers with children having disabilities have a poorer quality of life compared to their peers as reflected by the lower scores they obtained in the WHOQoL-BREF questionnaire. This is in agreement to the research work done by other authors as well [8,13,15-25]. It was observed that as age of the child increased, the quality of life of caregivers became better. It may be due to the fact that initially caregivers passed through a phase of denial which increased their own stress levels & commitments towards the child, but with time, acceptability of the fact and a self-learning process of coping developed. These findings did not correlate with the study done by Oliveira Ede F and Limongi SC who found no correlation between the age of the child and quality of life scores [17].

The present study agreed with the findings of other authors that there was no correlation between gender of the child and the quality of life scores in caregivers [18,19,21]. Middle aged caregivers (26-35 years) had poorer quality of life outcomes as compared to

younger ( $<25$  years) or older caregivers ( $>35$  years). This result was contrary to the finding of Barros ALO et al., According to them older caregivers had higher impact on quality of life due to disabled children [26]. The lower score was statistically significant in all the domains with respect to fathers belonging to the case group. Interestingly, only the scores obtained by mothers in domain 3, despite being lower than the scores achieved by mothers in control group was not statistically significant ( $p$ -value  $>0.05$ ). This finding is contrary to the studies done by Malhotra S et al., and Misura AK and Menisevic H, [18,24]. In 2017 Misura AK and Menisevic H, observed better quality of life scores in fathers of children with intellectual disabilities [24]. On the other hand, Malhotra S et al., found lower scores in all domains of WHOQoL-BREF in both parents as compared to control group [18]. The better scores were observed in present study in caregivers of case group residing in urban location contrary to findings of Shekhawat BS et al., [25]. The explanation of these findings lies in the fact that appropriate medical care is not available at village or even town level to deal with children having disabilities. Caregivers living in joint families had better scores as compared to caregivers of nuclear families in case group. This signified the importance of sharing burden in the joint families as mentioned in previous studies [20-24].

## Limitation(s)

There were many variables which were not taken into consideration as this study would have become complicated, hence limited and common factors were taken into account. In further studies other factors can be considered like jobs of caregivers, socioeconomic status etc., to study their effect on quality of life of caregivers of children with disabilities. Severity of disability was not considered in this study as all the disabled children and their caregivers were included during the mentioned period without considering the diagnosis as inclusion criteria. Many factors can be studied in isolation or in combination to find the cause effect relationship in such studies. Nevertheless, it is an established fact that caregivers of children with disability have lower quality of life scores in almost all domain as compared to caregivers of children without disabilities.

## Recommendation

Department providing health care management to children with disabilities should also have protocol for caregivers well being including education of caregivers regarding the disability of their child, its management and stress management.

## CONCLUSION(S)

The lower scores achieved by caregivers of children with disability underlies the fact that their quality of life has been affected by the added responsibility of bringing up their child. Lower quality of life equates to increased emotional, physical, mental and social problems which takes a toll on the overall health of caregivers. Herein lies the importance that health care practitioners apart from treating the child with disability should also address the problems being faced by the concerned caregivers in the form of appropriate and timely guidance. Psychological counselling, peer group meeting, exercises to improve muscle flexibility and core muscle strengthening, education on lifting techniques, de-stressing techniques like meditation etc. would go a long way in improving the health of the caregivers.

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