

Female Care Givers of Children with Cerebral Palsy: Quality of Life, Knowledge and Practice Regarding Ophthalmic Evaluation – A Study from Coastal Town of Southern India

VIDYA HEGDE¹, RASHMI JAIN², ANUPAMA BAPPAL³, RASHMI SHAMBU⁴, HIMANI KOTIAN⁵

ABSTRACT

Introduction: A family centered approach to the care of children with disability is a widely accepted concept. Traditionally in India, mothers or females in family are the primary care givers. Taking care of children with special needs may have an impact on the physical and mental health of care givers and hence it needs to be investigated.

Aim: To know the Quality Of Life (QOL) of female caretakers of children with Cerebral Palsy (CP). The study also assessed the knowledge of the caretakers about the need for ophthalmic evaluation of these children.

Materials and Methods: Thirty six consenting female care takers were administered self-designed validated questionnaire that had 22 items. It included demographic data and items to know the awareness amongst the caretakers regarding the need for ophthalmic evaluation to know the awareness amongst the caretakers regarding the need for ophthalmic evaluation. Chi-

square test was used to know the association between mean QOL score and age of care taker, educational qualification and number of children in the family. It was also used to know the association between the five domains and mean QOL score.

Results: The mean age of the study group was 31.39±0.707 years. Among the care givers, 41.66% were from rural background and 75% were unemployed. The mean QOL score was 40.47. Out of 36 participants, 20 (55.6%) had a mean score < 41 (good QOL), 16 (44.4%) had a mean score > 41 (poor QOL). Chi-square test showed significant statistical association between the mean QOL score and limitation of physical activities and burden ($p < 0.05$). Out of 36 participants, 24 were not aware about the need for eye examination of CP children.

Conclusion: The QOL of female caregivers of children with disabilities is influenced by several factors. There exists poor awareness regarding the need for ophthalmic evaluation among care givers.

Keywords: Awareness, Caretakers, Domains, Ocular health

INTRODUCTION

Cerebral Palsy (CP) is one of the common disorders with physical disability seen in childhood with reported incidence being 2 to 3 per 1000 live births [1-3]. In India, nearly 3.8% of the population has disability, of which about 15-20% of the total physically handicapped children suffer from CP [4]. CP is a chronic, non-progressive neurological injury, occurring during the development of the central nervous system. It can result from brain injury that occurs during prenatal, perinatal or postnatal periods. It may be associated with sensory and intellectual disabilities and is the most common cause of motor impairment in childhood [5]. Complications of CP include contractures, spasticity, fractures, feeding difficulties and gastrointestinal abnormalities. There is high prevalence of ocular defects in children with CP [6]. The goal of treatment is to improve functionality and sustain health which is achieved by treatment offered by multispecialty team.

Children with CP are dependent on others for their activities of daily living. Bringing up a child with CP causes considerable burden and stress in the family especially on the care giver. Traditionally in India, mother or females in family are the primary care givers. They also have responsibility of running the house and taking care of routine household activities. Care burden puts additional physical and mental stress on them. It can also lead to health related issues like depression. Several such studies report the extent of care burden, stress and impact on quality of parents [7-9]. It is important to assess the role of demographic and socio economic factors on the

health and QOL in care giver in Indian settings. Knowing these will enable the stake holders and policy makers to provide the required social and financial support to improve the QOL of care givers in developing country like India.

The aim of the study was to assess the QOL of female care takers of children with CP. The study also assessed the knowledge of the caretakers about the need for ophthalmic evaluation of these children.

MATERIALS AND METHODS

The research was designed as a cross - sectional study and data collection was completed over a period of one year from January 2015 to January 2016. It was conducted in the Department of Ophthalmology at a tertiary care centre after obtaining clearance from Institutional Ethics Committee. A self-designed questionnaire (annexure) was used to assess the QOL of primary care giver of children diagnosed with CP. This questionnaire was prepared after review of relevant research articles [7,10,11] and then validated for content by subject experts in the field of Ophthalmology, Community Medicine and Medical Education. Reliability of questionnaire was assessed using Cronbach's Alpha in SPSS Software version 22 and Cronbach's alpha was 0.885. Internal Consistency between the questions was good. The validated QOL questionnaire was translated into two vernacular languages- Kannada and Malayalam, which are commonly spoken in the field practice area of the hospital. This was planned as a time bound study, so all the care

givers of children with CP referred to Ophthalmology department, who consented, were enrolled in the study.

The children who have been diagnosed with CP were referred for ophthalmic evaluation by the Department of Paediatrics. The parents of the child were informed regarding the need of the study, ocular examination and the objectives of the study. They were informed regarding the questionnaire. They were clearly explained that refusal to participate would not affect the care given to their ward. The participants were also assured of confidentiality of information shared. Any doubts regarding the study protocol were clarified by the chief investigator. The female primary care giver was identified and was then enrolled in the study after obtaining their written consent.

On visiting Ophthalmology Department, ocular evaluation of children was performed that included pupillary dilatation for fundus examination. The interview was scheduled during this time to ensure that the family does not have to spend any extra time for the purpose of the study.

The questionnaire recorded the demographic details of the study participants including age, education, employment, socioeconomic status and number of children in the family. It included 22 questions that assessed following five domains- limitation in activities due to physical health problem, disrupted schedule, emotional problems, financial burden and anxiety [Annexure]. It also had questions assessing the awareness regarding ophthalmic evaluation of child with CP. Likert scale with score from 0 to 4 was used to grade 22 items. The total score hence ranged from 0 to 88. QOL score of 41 was taken as demarcation for categorizing the QOL of care givers as good and poor QOL.

STATISTICAL ANALYSIS

Descriptive statistics were used to describe the demographic details of study population. Chi-square test was used to determine the association between scored categorical variable and the domains under evaluation. The test was also used to know the association between mean QOL score and age of care taker, educational qualification and number of children in the family. Results were considered to be statistically significant at $p < 0.05$.

RESULTS

The questionnaire was administered to 36 consenting female care takers, age ranging from 22-55 years, while 20 (55.56%) were in the age group of 21-30 years. [Table/Fig-1] shows demographic characteristics of the sample population. It also depicts the socio economic class the participants belong to. This is based on Updated Kuppaswamy classification [12]. The educational qualification of female care takers were grouped as follows: Primary level (first to fifth standard), middle school (sixth to seventh standard), secondary (eighth to tenth standard), higher secondary (eleventh to twelfth standard) and Graduate. The results found in this study are depicted in [Table/Fig-1]. Among the care givers, 41.66% were from rural background and 75% were unemployed.

The mean QOL score was 40.47 with minimum being 15 and maximum 75. Out of the 36 participants, 20 (55.6%) had a mean score < 41 which was good QOL. Sixteen (44.4%) had a mean score > 41 which was poor QOL. The mean values and standard deviation of five domains are shown in the [Table/Fig-2]. Chi-square statistics test was used to find out statistical association between mean QOL score of care givers and area of residence, age and number of children, which is depicted in [Table/Fig-3]. These were not found to be significantly associated to QOL. Test was also used to find out relation between mean QOL score and educational qualification which was found to be insignificant (p -value-0.393). The test showed statistical significant association between limitation of physical activities, burden and QOL score as shown in the [Table/Fig-4]. Emotional domain did not show any statistical association with QOL score.

Variable	Attribute	Frequency (%)
Mean age of care giver (SD) in years		31.39±0.707
Relationship to child	Mother	35
	Grand mother	1
Place of residence	Rural	15 (41.66)
	Urban	21(58.33)
Number of children in family	1	8 (22.22)
	2	13 (36.11)
	3	12 (33.33)
	4	3 (8.33)
Educational Qualification of care giver	Primary	7 (19)
	Middle School	12 (33)
	Secondary	10 (28)
	Higher Secondary	2 (6)
	Graduate	4 (11)
Socioeconomic status (Modified Kuppaswamy)	Illiterate	1 (3)
	Lower	2 (5.55)
	Lower middle	1(2.78)
	Upper Lower	31(86.11)
	Upper middle	2 (5.55)

[Table/Fig-1]: Demographic characteristics of study population (N = 36).

Domains	Range	Mean value	Standard deviation
Emotional	2- 15	8.83	4.09
Physical	2 – 17	9.53	3.92
Disrupted schedule	0-15	7.14	3.49
Burden	3- 14	7.81	3.58
Anxiety	2 – 10	6.14	2.42

[Table/Fig-2]: Mean value and standard deviation of the domains in care takers.

	QOL	Attribute		Pearson chi-square value (df)	p-value
		Urban	Rural		
Residence	Good	11	9	0.26 (1)	0.65
	Poor	10	6		
Age (years)		30 or less	More than 30	0.83 (2)	0.66
	Good	11	9		
	Poor	9	7		
Number of children		<02	>02	0.47 (3)	0.92
	Good	12	8		
	Poor	9	7		

[Table/Fig-3]: Relationship between care givers' quality of life and area of residence, age and number of children.

The analysis of questionnaire to know the awareness amongst the female caretakers regarding the need for ophthalmic evaluation of CP children showed that 24(67%) were not aware. Amongst the care takers who were aware, 30% received the information from the doctor. Their perceptions regarding ophthalmic evaluation of CP children are shown in [Table/Fig-5].

DISCUSSION

Caregiving is part of parenting and when the requirements are excessive and long lasting, this can often cause significant burden. This in turn may adversely affect the physical and psychological health of caregivers [13], thus possibly reducing their QOL [14]. The mean age of female care takers in this study was 31.39 years. The mean age reported by Shanbagh D et al., and Yilmaz H et al., was 37.8 years and 35.96 years respectively [7,15]. However, a study

	Chi-Square Statistic (df)	p-value
Physical		
Bathing	10.89 (4)	0.03*
Feeding	10.49 (4)	0.03*
Attending function	14.81 (5)	0.01*
Dependency	10.04 (4)	0.04*
Wearing spectacles	11.01 (6)	0.09
Emotional		
Stress	6.61 (4)	0.16
Support	5.19 (4)	0.27
Worry	8.43 (4)	0.08
Feeling depressed	8.23 (4)	0.08
Disrupted schedule		
Household chores	7.51 (4)	0.11
Going to market	14.39 (6)	0.03*
Travel in public transport	15.46 (4)	0.004*
Disturbed sleep	3.40 (4)	0.49
Burden		
Economic stress	9.95 (4)	0.04*
Expenditure	8.29 (3)	0.04*
Special school	10.25 (5)	0.07
Make child learn	18.25 (6)	0.006*
Illness management	9.65 (4)	0.04*
Anxiety		
Child with disability	13.23 (3)	0.004*
Relaxation time	12.37 (4)	0.02*
Conceive again	11.06 (6)	0.09
Communication	8.97 (4)	0.06

[Table/Fig-4]: Association of domains with the mean score using Chi-square test. p-value < 0.05 is considered significant shown with*.

	Attribute	Frequency (%)
Awareness regarding need for an eye checkup	Yes	12 (33%)
	No	24(67%)
Source of information	Doctor	11(92%)
	Friends	1(8%)
Association of Refractive errors	Yes	5 (13.9%)
	No	31(86.1%)
Presence of Squint	Yes	5 (13.9%)
	No	31(86.1%)
Presence of Cataract	Yes	1 (2.8%)
	No	35(97.2%)
Ophthalmological Consultation sought for child in tertiary hospital	Yes	21(58.3%)
	No	15(41.7%)
Reason for consultation	Referred by doctors/ paediatrician	17(81%)
	Self	4(19%)
Willingness to take child for regular eye examination	Yes	22(61%)
	No	14(39%)

[Table/Fig-5]: Knowledge and practice amongst female caretakers, regarding the ophthalmic evaluation of cerebral palsy children.

done by Marron EM et al., showed a higher mean age (41.98 years) of care givers [16]. Educational qualification did not have an impact on QOL.

In our study 55% of care givers had a mean QOL score less than 41, which indicated good QOL. The reason for this could be that some families may cope well despite the challenges involved in caretaking. Majority of the respondents in this study were not working.

A family centered approach to the care of children with disability is widely accepted concept. Parenting style is an important aspect for children with CP. A study done in Ontario, Canada, on the caregivers of children with CP, showed more reported distress, chronicity of distress, emotional problems and cognitive problems of caregivers [17]. In a study done in Bangladesh, Mobarak R et al., found that 41.8% out of the 91 mothers of children with CP had a risk for psychiatric morbidity. [18] A study done by Shanbagh D et al., showed psychological and environmental domains of QOL to be most affected, while the physical and social domains were relatively better [7]. Our study showed statistical significant association between limitation of physical activities, burden and QOL score. Children with CP may find it difficult to perform self-care like dressing, feeding, bathing and mobility. Greater disability may demand more effort from the caregivers, and hence take up more time and money. The financial burden involved in taking care of these children is huge apart from the responsibility of meeting the self-care requirements.

Visual morbidity is frequently associated with CP [6,19]. Majority of the care givers in our study were not aware of the need for ophthalmic evaluation of children with CP as they were unaware of ocular associations with the illness. They need to be better informed about the disability affecting these children. Probably limitation of physical activities takes precedence in these children and the ocular health goes neglected. Studies have shown that knowledgeable caregivers are likely to report positive psychosocial indices and better health-related QOL [20]. Appropriate care can be given if caregivers have adequate knowledge about the child's condition. Therefore, healthcare professionals play an important role in imparting health education. There are studies which have improved the parental knowledge about CP through educational films, flash cards and educational workshops [21-23]. At the community level it is essential to sensitize the care takers about the condition through educational videos, flip charts or posters.

LIMITATION

The study was time bound with limited sample size. It did not take into account the type of CP and its Gross Motor Function Classification which could have been co-related with the QOL. We did not consider the number of hours of care giving.

CONCLUSION

Overall the QOL of the care givers in this study was good. Of the various domains assessed, burden and limitation of physical activities affected the mean QOL score. The study highlights the need to do more research on QOL of female caretakers of CP. Providing information about the condition to the caregivers can help to improve their self-confidence and coping skills. In India as most of the caregivers are from rural area, it is needed to impart health education with the help of healthcare professionals. The fact that there was poor awareness regarding the need for ophthalmic evaluation of CP children needs to be addressed.

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- a) Not at all b) Slight c) Moderate d) Very much e) Extreme
- 7. Do you have difficulty attending social function or visiting friends and relatives with the child? (PHYSICAL)**
- a) Not at all b) Slight c) Moderate d) Very much e) Extreme
- 8. To what extent do you get the support you need from your friends and relatives in managing the child? (EMOTIONAL)**
- a) Extreme b) Very much c) Moderate d) Slight e) Not at all
- 9. How often do you worry? (EMOTIONAL)**
- a) Never b) Seldom c) Often d) very often e) Always
- 10. How often do you feel depressed? (EMOTIONAL)**
- a) Never b) Seldom c) Often d) very often e) Always
- 11. How often do you feel the child would be a burden to the family? (ANXIETY)**
- a) Never b) Seldom c) Often d) very often e) Always
- 12. Is the child dependent on medications? (PHYSICAL)**
- a) Never b) Seldom c) Often d) very often e) Always
- 13. How much are you economically stressed in providing the treatment needed for this child? (BURDEN)**
- a) Not at all b) Little c) Moderate amount d) Very much e) Extreme amount
- 14. How much of the monthly income of the family is spent on the treatment of the child? (BURDEN)**
- a) Not at all b) Little c) Moderate amount d) Very much e) Extreme amount
- 15. How much are you economically stressed, if your child is attending special school? (BURDEN)**
- a) Not at all b) Little c) Moderate amount d) Very much e) Extreme amount
- 16. How much time do you get to relax? (ANXIETY)**
- a) Extreme amount b) Very much c) Moderate amount d) Little e) Not at all
- 17. How safe do you feel to have another child? (ANXIETY)**
- a) Extreme amount b) Very much c) Moderate amount d) Little e) Not at all
- 18. To what extent is your sleep affected because of the disturbed sleep of the child? (DISRUPTED SCHEDULE)**
- a) Not at all b) Little c) Moderate amount d) Very much e) Extreme amount
- 19. How difficult do you find to make the child learn? (BURDEN)**
- a) Not at all b) Little c) Moderate amount d) Very much e) Extreme amount
- 20. How difficult do you find to communicate with the child? (ANXIETY)**
- a) Not at all b) Little c) Moderate amount d) Very much e) Extreme amount
- 21. If your child has been advised spectacles, how difficult is it for you to make sure that the child wears them properly? (PHYSICAL)**
- a) Not at all b) Little c) Moderate amount d) Very much e) Extreme amount
- 22. If you have illness, how much is its management affected because of having a child with this disorder? (BURDEN)**
- a) Not at all b) Little c) Moderate amount d) Very much e) Extreme amount

ANNEXURE

Questionnaire on quality of life of female care takers of cerebral palsy children

1. How stressful are you with having a child with this disorder? (EMOTIONAL)

a) Not at all b) Slight c) Moderate d) Very much e) Extreme

2. How difficult is it to bathe your child? (PHYSICAL)

a) Not at all b) Slight c) Moderate d) Very much e) Extreme

3. How difficult do you find to feed your child? (PHYSICAL)

a) Not at all b) Slight c) Moderate d) Very much e) Extreme

4. How difficult do you find it to do your household chores because of the child with this disorder? (DISRUPTED SCHEDULE)

a) Not at all b) Slight c) Moderate d) Very much e) Extreme

5. Do you have difficulty taking the child out along with you to shops or markets? (DISRUPTED SCHEDULE)

a) Not at all b) Slight c) Moderate d) Very much e) Extreme

6. Do you have difficulty taking the child in public transport? (DISRUPTED SCHEDULE)

a) Not at all b) Slight c) Moderate d) Very much e) Extreme

Questionnaire to know about the awareness regarding the need of ophthalmic examination amongst care takers of cerebral palsy

1. Are you aware that children with cerebral palsy need an eye checkup? Yes /No

2. If yes, how did you get this information?

3. Are you aware of different eye disorders which can affect children with cerebral palsy?

a. Refractive errors - Yes/No

b. Squint - Yes/ No

c. Cataract - Yes/ No

4. Have you taken your child to a tertiary hospital for eye checkup? Yes/No

5. Why did you take the child for the eye checkup?

6. Would you take the child for regular eye examinations as advised by your ophthalmologist? Yes/No

PARTICULARS OF CONTRIBUTORS:

1. Professor, Department of Ophthalmology, Yenepoya Medical College, Mangalore, Karnataka, India.
2. Associate Professor, Department of Ophthalmology, Yenepoya Medical College, Mangalore, Karnataka, India.
3. Associate Professor, Department of Ophthalmology, Yenepoya Medical College, Mangalore, Karnataka, India.
4. Assistant Professor, Department of Ophthalmology, Yenepoya Medical College, Mangalore, Karnataka, India.
5. Lecturer cum Biostatistician, Department of Community Medicine, Yenepoya Medical College, Mangalore, Karnataka, India.

NAME, ADDRESS, E-MAIL ID OF THE CORRESPONDING AUTHOR:

Dr. Rashmi Jain,
Associate Professor, Department of Ophthalmology, Yenepoya Medical College, Mangalore-575018, Karnataka, India.
E-mail: drashmjain@gmail.com

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