

Factors Influencing Quality of Life of Children with Cerebral Palsy - A Qualitative Study

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ABSTRACT

Background: Cerebral Palsy (CP) is one among the most common childhood disabilities with varying clinical outcomes and can have profound effects on the daily life of children and their families. There are many possible factors that affect the health related quality of life (HRQOL) in childhood CP.

Aim: To explore the factors influencing the health related quality of life of children with cerebral palsy

Materials and methods: An explorative design was used for the study. Four focus group discussions and twenty in depth interviews were conducted with mothers of children with cerebral palsy and experts related to the care of children. Study subjects were selected based on criterion sampling from the CP Clinic and Neurology OPD of a tertiary care center, and special schools in Thiruvananthapuram District, Kerala. Qualitative thematic analysis was used for interpreting the data.

Results: Four major themes emerged (1) the disabled child, (2) competence of caregiver, (3) support system and (4) expert management. Barriers and promoting factors of health-related quality of life of children with cerebral palsy were also described in the study.

Conclusion: The study emphasizes importance of social, emotional, economic and therapeutic support system to be provided to the children with CP as well as their caregivers in maintaining good health related quality of life.

Key words: Quality of life, cerebral palsy, factors.

INTRODUCTION

Cerebral palsy (CP) is the most common physical disability in childhood and is considered to be a permanent disorder of movement and posture¹. Children with CP not only have to contend with a range of physical problems such as weakness, stiffness and clumsiness, but also face a range of social and emotional problems, such as peer rejection, depression, frustration, anxiety and anger which adversely influence their quality of life. QOL is defined as “the individual’s perceptions 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, and concerns”². It is influenced by varying factors which were studied in detail quantitatively in many studies. Sociodemographic and health-related factors like increase in the degree of disability and presence of complications decreased the children QoL while the availability of health insurance improved it.³ Functional limitations, self-care difficulties, behavioural problems, seizures, cognitive, sensory, social and emotional impairments and difficulties of daily life activities can affect health related quality of life in children and adolescents with CP.⁴

MATERIALS AND METHODS

A qualitative exploratory study was carried out. Four focus group discussions were conducted with mothers of children with

cerebral palsy attending the Cerebral palsy clinic in Department of Physical Medicine, Pediatric Neurology OPD of a tertiary care center, and selected special schools in Thiruvananthapuram District. The number of sessions was determined based on data redundancy.

Twenty in depth interviews were also conducted with mothers of children with CP and health care providers and experts involved in the care of the child to obtain more credibility and authenticity to the data collected. Criterion sampling was adopted to select mothers for in depth interview. Mothers who belonged to different socioeconomic status and having children with varying severity of disease, age and gender were included. Experts included one pediatrician, one physiatrist, one occupational therapist, two physiotherapists, and five teachers from special schools.

Data collection

The data were gathered through focus group discussions (FGDs) and in-depth interviews (IDIs).

One group consisted of 6-8 participants in FGDs. The researcher explained the purpose of conduct of the discussion and informed consent was obtained. Later the questions were presented to the group. Follow up prompts were used which were open ended so as to stimulate interactive discussion between group members. Active participation was encouraged. The duration of each discussion ranged from 45 to 60 minutes. Important points were summarized at the end of the discussion.

The interview guide consisted of the open-ended questions and probes. The interviews were conducted in Malayalam. Each interview lasted for 25–40 minutes. The interviews were digitally recorded after

obtaining consent. The consolidated criteria for reporting qualitative research (COREQ) were followed for reporting.

Data Analysis

Qualitative thematic analysis was used for interpreting the data. The digitally recorded data were transcribed verbatim and translated into English. Through reading and rereading of the transcripts, the researcher got familiarized with the data type and content. Preliminary codes were assigned to the data in order to describe the content. The codes were collated into broader themes. Recurring themes were identified, reviewed and refined. In this iterative process similarities and differences were identified, the meaning units were condensed further and themes were finalized. Subsequently four themes which demonstrated the core meaning of texts were identified. Each theme was reviewed for its credibility.

Ethical Considerations

The institutional ethical committee of Government College of Nursing, Trivandrum approved the study. Before data collection the purpose of the was explained to the interviewees and they were informed about their right to withdraw from the study at any point in time. Written consent was obtained from each interviewee. The privacy and confidentiality of the interviewees were maintained throughout the interview

RESULTS

Four major themes emerged. (1) The disabled child, (2) Competence of caregiver, (3) Support system and (4) Expert management. The findings are presented under each theme with subthemes and participants' quotes.

Table 1. Theme 1. The disabled child

Theme	Subthemes	Reported barriers of HRQOL	Reported facilitators of HRQOL
The disabled child	Immobility	Spasticity and contractures Severity of illness Poor financial status	Regular physiotherapy Consistent treatment Contracture release surgery
	Complicating conditions	Availability of specific therapy being restricted to tertiary care centers Recurrent refractory seizures Intellectual and sensory deficits	Specialized equipment Correction of sensory deficits Anti-seizure medications Adapted home environment

	Behavioral changes Social isolation	Malnutrition Patronizing attitude of others Chronic illness Poor social interaction being restricted to home Inability to communicate	Attending school Improving participation Availability of speech therapy
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Theme 1: The disabled child

a) Subtheme: Immobility

Majority of participants reported mobility restriction as the most important factor affecting health related quality of life. It extended from quadriplegia to minor movement restrictions. Total body involvement made the child bed ridden and dependent.

“When other children walk around, my child lies down, he can’t even turn and look at me. He does everything in the bed itself. He makes some peculiar sound when he is in need of something.”-mother.

“My child cannot sit up, speak, or see properly, (weeping). When his twin brother comes near, he tries to lift the neck, but fails, the other one beats him, but he can only cry or smile.”-mother

b) Subtheme: Complicating conditions

Co morbidities like seizures, intellectual impairment, sensory deficits etc. made the basic disability more worsen. This also made the caregiver hesitant in continuing home management.

“This child gets seizures every now and then. I am giving medicines regularly; but don’t know what is wrong. I think he can do well if seizures are controlled”-mother

“My son develops fever and cough very often. Last year he was admitted in intensive care unit. He was very serious”-mother.

c) Subtheme: Behavioural changes

Some children with cerebral palsy exhibited behavioral changes which included externalizing problems like disruptive and aggressive behaviors, and internalizing changes including depression, anxiety and discomfort that may not be evident to others. Mothers reported that if these

behaviors were not there, they could better manage the kids. They also reported inhibition to take the child out as they felt embarrassed before others.

“When his demands are not met, he reacts violently. He shouts and pulls my hair. It would have been easier to look after him if he behaved properly”- mother

Some experts opined that these changes in behavior may not be very evident in majority of CP children except in few with intellectual impairment.

d) Subtheme: Social isolation

The social interaction of cerebral palsy children was restricted due to their disability. Majority were confined to home as it was difficult for the teachers to manage them at school and for parents to be with him at school all time around. But the treating personnel thought that schooling would definitely improve the child’s social quality of life.

“Parents overprotect the child thinking that they are not normal. They cocoon him more which makes him unable to experience the environment. The society also thinks similarly. It looks more for their defects than their abilities. Basically play which is most important for developing children are restricted for them”- psychiatrist

Speech defects were very common. Majority of cerebral palsy children had difficulty to communicate; many just make sounds. Inability to communicate also made the child more socially separated.

“Social interaction depends upon the mother. Some take the child everywhere; send him to school, but some of them keep him at home, hostels or special schools”- Principal, special school.

Table 2. Theme 2. Caregiver competence

Theme	Subthemes	Reported barriers of HRQOL	Reported facilitators of HRQOL
Caregiver competence	Awareness	Lack of information regarding care	Training from hospitals and health workers
	Attitude and willingness to care	Negligence Overprotection Apprehensive regarding child's future	Attitude in promoting child's independence Physical support for activities
	Caring skills	Lack of support from spouse and in-laws Poor physical and mental health of caregiver	Feeding skills Supervision for mobilization and leisure activities
	Ability to cope with stress	Unable to go for a job Other dependents at home	Social activities of caregiver Ability to tap resources

Theme 2: Caregiver Competence

a) Subtheme- Awareness

Mothers thought that if properly informed they could better look after children.

“Some complications of children develop due to ignorance of mothers. I felt like having some extra energy drink to make mothers understand facts regarding the child care. But once they are aware, they start doing better and try to learn more”-school teacher.

“We never knew that it was fits. It took four months for finding out what was wrong with the child. I think if we could identify it earlier his condition would not have been this worse.”-mother.

“We are given classes at the block resource centers. So I know that physiotherapy will help my child. In the PTA meetings we were told regarding pension and scholarship”-mother.

b) Subtheme: Attitude and willingness to care

Cerebral palsy children who were cared well from the beginning demonstrated better health and minimum complications. Determination and endurance of mothers played an important role.

“Mothers are doing so much for these children even though not supported by husband/family members. When I see the hardship of mothers, my efforts are so less. Their duty is not restricted to any time, it is day and night and lifelong. Their patience needs to be appreciated”- Special school teacher.

Exceptions were there where some mothers took the child's condition with less importance and were negligent in caring

them which led to many complications in the child.

“But some mothers think that child is a source of earning, in the form of pension”-school teacher.

c) Subtheme: Caring skills

Many mothers reported giving therapy at home difficult as the child resists due to pain and is hard for them to force the child.

“I can't take the child for physiotherapy daily as the centre is far from the house. I am scared to do it for her at home; she is very tight”-mother

The training given at school and hospital needs be continued at home by mother was very important for positive effects.

“Through repeated training we somehow make the child do some activities, but at home no reinforcement is given by parents. So we have to repeat the efforts again and again. Mothers tend to overdo and make the children dependent”- Teacher, special school

d) Subtheme: Ability to cope with stress

Having a sick child at home was a stressor for majority of mothers. Earning mothers are forced to leave their job to look after their dependent child. They feel sorry for the siblings whom they cannot look after properly as they are always engaged. They cannot go out as the child is alone at home are dependent wholly on mother. Ability of caregivers to withstand stressful situations and efforts to provide best care positively affected the child's quality of life

“Only my daughter knows how to give feed through the tube, what medications to be

given, so she never goes anywhere, always remains with the child” – grand mother
 “When he becomes sick, I get tensed that something wrong may happen to him. I

always pray that no other children develop such condition.”-mother

Table 3. Theme 3: Support System

Theme	Subthemes	Reported barriers of HRQOL	Reported facilitators of HRQOL
Support system	Family support Social support Educational support Financial support	Child and mother being abandoned Lack of awareness regarding supportive measures Lack of trained persons and equipment at normal school Inconsistent supply of funds & insurance Misuse of financial support	Support by family members and neighbors Family values Skill training by SSA at schools and home Financial support from various sources Social security measures

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 Theme 3: Support System

a) Subtheme: Family support

Mothers reported more confidence in the care of children when they are supported by their spouse and relatives. In some cases, fathers took a lead role as care giver.

“The only relief is that his father takes good care of him; even better than me”-mother.

“Family can do a lot. Supporting each other reduces stress. Entire family’s values and attitude count in the care of a sick child. Siblings are taught how to look after their sick brother or sister”- physiotherapist.

Few participants expressed abandonment and rejection or lack of support from family including spouse. “Nobody from my husband’s family gives support. Even my mother hasn’t accepted, and she doesn’t want to hold him.”- mother

b) Subtheme: Social support

Support by society and community was beneficial for the child, but majority of participants denied receipt of any such assistance. Financial support was available for some of the families from religious agencies like church. It was also beneficial when a neighbor agreed to look after the child when mother had to go out for some important family matters.

“Looking after a child with disability is very costly when compared to a normal child”-mother

“NGOs are doing a great job for helping such children. Provision for weekly physiotherapy at home by field workers should be made for bedridden children. There are meetings held for parents of CP

children at this office in which common problems are discussed.” - teacher.

c) Subtheme: Educational support

Schooling was mentioned as an important factor for improving child’s social interactions. Both care providers and mothers agreed upon this fact.

“Majority are normal who can be sent to normal school. Only around 30% are mentally retarded, rest can do well at school. You don’t really need to consider them as disabled children; They should be considered as normal children with difficulty in movement”. Physiatrist

Mothers also agreed that sending the child to school was beneficial, but it was difficult to manage children with severe cerebral palsy at school.

“Those with moderate to severe cerebral palsy can’t attend schools regularly. Admission is done at school for namesake, may be to avail the benefit. Many are not attending”-mother.

d) Subtheme: Financial support

Parents reported that they had difficulty in understanding the complex web of potential financial, education and mobility benefits. Even though these benefits were permitted there was no consistency as the funds were allotted once in a while. The regulations should be greatly simplified or there should be a more proactive attitude from public services to help families take advantage of what they are entitled to.

“People should be aware of facilities available to them. Some people go after money more. So they know how to process it. But some are not aware of any supports. They need to be guided in such matters at the schools, Akshaya centers” – physiatrist. Participants agreed that government was extending assistance in the form of health

insurance policies, disability pensions etc. But many are not aware regarding how to tap the resources.

“All mothers are not aware of the benefits. Homebound children may not benefit unless someone inform parents while attending hospital, schools, camps etc.”-occupational therapist

Table 4. Theme 4. Expert management

Theme	Subthemes	Reported barriers of HRQOL	Reported facilitators of HRQOL
Expert management	Early advanced treatment Access to care Consistent care	Inconsistency in care Inadequate supply of drugs and orthotics Difficulty in access to specific treatment Difficulty in transportation to distant tertiary care centers	Early intervention Individualized therapy Botox injections and contracture release Antispasmodic medications

Theme 4. Expert management

Subthemes- Early stimulation and advanced treatment, access to care and consistent care

a) Subtheme: Early stimulation and advanced management

Expert management right from diagnosis of the child could improve the general health of the child and reduce complications. Child health screening and early intervention services are available in tertiary as well as District Early interventions centers.

“The intervention should start off as soon as you find that the child is a case of CP. Early stimulation is basically stroking, moving the limbs, playing with the child, improving the visual and hearing sensation and helping the child to move around” – therapist.

Mothers reported a notable change in the child’s condition after the initiation of therapy for the child.

“A small surgery was done in his legs which made such an improvement in his walk; I feel that now he can do much better”- mother.

b) Subtheme: Access to care

A challenge noted in acquiring early and expert management was its availability being restricted to few centers and are not accessible to many children. Some of them are not aware of these services.

“A combined effort of many specialists makes the management more effective and efficient. Babies born in a tertiary centre are followed up well as per protocol. But those who are born at the peripheral level are not benefited like this. The diagnosis

and referral to the specialist take around some years. Many parents try going for Ayurvedic massage and other mode of treatments”- pediatrician.

c) Subtheme: Consistent care

Not only the initiation of therapy, but compliance to it was another factor influencing the child’s improvement. Parents are motivated for continuing the care when they get constant support from the family as well as hospital.

The participants reported feeling disappointed when the doctor (physiotherapist) spent a lesser amount of time with the child, since they had travelled long distances and faced multiple difficulties in bringing the child to the hospital.

“I have to start around 4 am from home with the child to attend the cerebral palsy clinic usually in a hired vehicle. A change in routine irritates the child. When compared to the hardships of reaching the hospital the service provided to the child may be very less; the main doctor whom I am expecting for the consultation may not be available on that particular day”- mother.

DISCUSSION

The physical disability was a major detrimental factor of health related quality of life of CP child reported by participants. Children were bedridden or restricted with

their mobility. Similar experiences were shared by mothers of CP children in Bangladesh in a qualitative study. Participants stated that physical functioning related to activities of daily living was their greatest healthcare need.⁵

Mothers reported that their children expressed anger, fear and hyperactivity. They found it difficult to look after children with behavioral problems. Presence of internalizing behavior was associated with lower HRQOL scores for children with CP. Mothers expressed the need for social inclusion and participation for their child with CP. Similar suggestion was put forward by a qualitative study conducted in Australia, exploring multiple perspectives of school success and participation for students with cerebral palsy. An inclusive school culture was crucial to students with cerebral palsy.⁶

Need for improving the care giver competency was supported by another study which found that the development of parental empowerment and capability was a dynamic process and health care professionals should help parents feel more capable by incorporating a user-friendly approach, which fitted easily into their daily routines and by training courses to assist with therapy implementation, and the correct resources within the home.⁷ Favorable maternal attitude and skills facilitated the quality of life in CP children. Similar findings were observed in an exploratory study in Gujarat where most of parents including fathers expressed love and deep affection for child. Adverse parenting practices were associated with mental health issues and other negative consequences for child psychological development.⁸

Spousal support was more significant as it maintained the emotional health of both mother and the child; but some mothers were devoid of such support. Similar situations were reported by mothers in Zambia where they experienced a lack of acceptance of the child and embarrassment, especially by the male spouses, as well as from relatives.⁹

Mothers reported that even though many supportive measures were provided by government in the form of social security measures they could not utilize it due to many obstacles in practically accessing it. In agreement to this, a qualitative study reported difficulty accessing support. None of the Danish parents thought they received any advance information as to what they might need for their children. Furthermore, they felt that social workers did not know enough about the specialist field of CP.¹⁰

Common barriers to access to community-based fitness programs for children with cerebral palsy included inaccessible physical environments, lack of trained personnel and modified equipment, difficulty with accessing information about programs, inability to pay for membership fees, and transportation barriers.¹¹

CONCLUSION

Measures to improve the health related quality of life of children with cerebral palsy could not hit the target as resources were insufficient. Less manpower to look after the child at home and to take him for treatment regularly, less fiscal power to afford to advanced specific treatment, less material power sufficient to be given to all children with cerebral palsy at the treatment centers and less organizational power to ensure that all the disabled children are provided with sufficient resources and schooling and to empower the caregivers with sufficient information and training. Many of the barriers reported were environmental and modifiable. The development of strategic partnerships with health care providers and political systems might facilitate solutions to address access barriers.

Declaration by Authors

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