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Original Research Article

A qualitative study to conceptualize levels of awareness, acceptance and expectations in parents of children with cerebral palsy in Gujarat, India

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ABSTRACT

Background: Caring for a child with a disability presents a multifaceted challenge for managing and coping with the child’s functional limitations and possible long term dependence to the caregiver and family. A wide range of psychosocial problems are experienced by the parents of children with CP. As an important member of the rehabilitation team, Physiotherapists comes in regular and long term contact with family and care givers of the CP child. This increase responsibilities of a physiotherapist from more than just dealing with sensory-motor rehabilitation of a CP child to understand need and expectations and guide/counsel the caregiver, parents or family as and when needed. Studies like this can provide valuable information for designing a family centered care program for children with CP. Objective of present study was to identify the main concepts which represent levels of awareness, acceptance and their expectations in parents of children with cerebral palsy in Gujarat.

Methods: Qualitative research design using in-depth semi structured interviews was used for the study. Total 21 parents were selected using purposive sampling and were interviewed till data saturation was achieved. The main descriptive elements regarding their levels of awareness, acceptance and expectations were extracted using content analysis method.

Results: Common themes such as disturbed social relationships, health problems, financial problems, worries about future of the child, need for more support services, and lack of adequate number of trained physiotherapists were experienced by the parents.

Conclusions: A wide range of experiences were described by the parents of children with CP. Studies like this can provide valuable information for improving depth and quality of rehabilitation services by a physiotherapist through a family centered care program for children with CP.

Keywords: Awareness, Acceptance, Cerebral palsy, Expectations, Family centered care, Parents

INTRODUCTION

Cerebral palsy is primarily a disorder of movement and posture. It is defined as an “umbrella term covering a group of non-progressive, but often changing, motor impairment syndromes secondary to lesions or anomalies of the brain arising in the early stages of its development”.[1] Caring for any child involves considerable resources, but the demands for these resources are often increased when caring for a child with a disability. Managing and coping with the child’s functional limitations and possible long term dependence whilst dealing with everyday living and the needs of the whole family, have implications for the psychological and physical health of the caregiver.[2] Parents are challenged with great tension and struggle, which leads to failure to take care of themselves, their children and other family members.[3,4]

Parents of children with disabilities experience psychological issues such as stress, anxiety, internal conflicts, sense of loneliness and worries and social problems such as accessibility to healthcare and education services, difficulties in inclusion of child in school and community, financial strain, lack of public awareness and stigma.[2,5-8]

Knox (2008) has suggested that the real social picture regarding cerebral palsy and the worries and expectations of parents of children were understudied.[9] Previous studies have studied the parents' mental health and quality of life in more or less quantitative manner and have found that mothers of children with cerebral palsy have higher prevalence of depression high stress levels, and a significant relationship between their quality of life and the type and amount of disability of their child's cerebral palsy.[10-16] Previous study by the author has suggested that levels of stress and depressive symptoms are high in the parents of children with cerebral palsy as compared to the parents of healthy children.[17] Hence, because of the parents' important role in supporting and caring of the afflicted children, the amount of awareness, acceptance, psycho-social challenges being faced by them and their expectations from rehabilitation services should be studied in extensive and exploratory manner. This will help in identification of primary concepts related to the said aspects and serve as guide for designing a family centered care program for children with CP.

The objective of this study was to identify the main concepts and themes which represent levels of awareness, acceptance and their expectations in parents of children with cerebral palsy in Gujarat.

METHODS

This qualitative study was designed to conceptualize the cardinal factors related to awareness, acceptance and expectations in the parents of children with cerebral palsy using the content analysis method for broad description of a phenomenon [18,19]. In particular we conducted in-depth interviews with participants who were selected from parents currently receiving services for their children at outpatient physiotherapy centers in Ahmedabad and Vadodara to identify said aspects in parents of children with cerebral palsy. The Participants included parents of children aged 0-12 years who are clinically diagnosed as having cerebral palsy. The exclusion criteria were: unwillingness of the parents to participate, parents of children with other disorders, parents diagnosed with psychological and cognitive-behavioral illness, parents with long history of diagnosed medical condition or illness.

The eligible parents were selected for interview between June 2016 to December 2016 using purposive sampling after obtaining informed consent from them. Total 21 parents were interviewed in Gujarati using a semi structured adjustable, interview guide format (Appendix 1), until the data were saturated. The main domains for the interview were determined by extensive literature review and were inclusive of categories related to socio-demographic, psychological, emotional and social categories. Moreover, the interview guide was reviewed by 4 physiotherapists, 1 community medicine expert, 1 Rehabilitation Psychologist, 1 Occupational Therapist, 1 Pediatric Neuro-physician, 1 Pediatric Orthopedic Surgeon and 1 pediatrician to ensure face validity.[20-22] The interview format was kept adjustable to provide flexibility for use of heuristic questions such as, "Explain more." or "What do you mean exactly?" The responses were audio recorded and briefly noted during interview and transcribed immediately after the interview was completed. The duration of interview varied from 60-90 minutes and each parent was interviewed in 1 or 2 sessions as per need.

Analysis

The main descriptive themes required to analyze the interviews through method of Graneheim et al by the author. The verbatim transcription of the interview was read several times (familiarization) and then the respondents' viewpoints, recurrent statements and experiences were extracted in relation to the context (condensation). Then the whole data were indexed or coded to categorize the concepts in the respondents while preserving the core (indexation). The data were then reconstructed based on the index at a more abstract level using reduction and induction method (abstraction).[23,24]

RESULTS

All but two of the participants in the interviews were mothers of children with CP, who were shouldering the responsibilities of caring for their children (Primary Caregivers). The socio demographic profile of the participants is depicted in Table 1.

On analysis of the transcript of the interviews, the following themes emerged.

Awareness in the parents

Awareness regarding cerebral palsy, its causes and prognosis

Most of the parents said that they knew about the condition named as Cerebral Palsy but considered it to be associated with mental and developmental problems rather than acknowledging it to be associated with brain damage caused by various reversible causes. A father explained, "Before having this child we didn't know what it is and how it occurs, but we have seen cerebral palsy children in movies and in news and newspapers. But now we know that there are many reasons for its occurrence and it could have been prevented." Many of the parents interviewed showed optimism regarding the future of the child and told that, "Our medical consultant and therapists have provided us with assurance regarding improvement in our child's condition. We hope our child can live normal life as others."

Table 1: Socio demographic profile.

Study participants	
No. of participants	21
Mean age (years)	35.85
Occupation	
Housewives	18
Working	3
Type of family	
Joint	15
Nuclear	6
Mean no. of family members	6.17
Mean no. of children	1.86
Children of participants	
Mean age (years)	6.57
Sex	
Male	14
Female	07
Type of diagnosis (topographical)	
Spastic diplegic	13
Hemiplegic	2
Quadriplegic	3
Athetoid	2
Dyskinetic	1

Awareness regarding the available treatment options

Almost all parents agreed to need of undertaking more vigorous measures for spreading awareness regarding the causes and treatment services available for children with Cerebral Palsy. There were certain misconceptions regarding therapy and medications such as, "When they said I need regular physiotherapy for my child, I thought how the exercises and machines may help my child develop. Why should I go for it, isn't there any medicine available to increase strength of muscles and make them move easily?" Many of them approached the religious priests, vaidyas, bhuvas etc for faster and better recovery of their child.

Awareness regarding role and importance of Physiotherapy intervention

Most common theme reported was that knowledge regarding role of physiotherapy in treatment of cerebral palsy was limited to just the movements, stretching and exercises rather than understanding the detailed role played by it in developmental assistance and functional independence. One of the parents also preferred physiotherapy over conventional medical therapy because of their past exposure to physiotherapy service setup.

Awareness regarding support and aid provided by social institutions

Almost all of the parents were not taking any kind help or aid from any government or non-government institution. The reason as explained by most of them was their lack of detailed knowledge regarding existence of any such provisions from other institutions. "We need financial support because my husband is the only bread earning member of the family and we have 2 elder girls to take care of along with my father-in-law and mother-in-law. We have to think about educating them and marrying them in future. But we have never been asked by anybody if we need any help or never been explained if anyone can provide us such help." Many mothers informed that in spite of being economically stable enough to bear the costs of daily living and treatment of child, additional and sudden expenses cause certain trouble in that stability.

Acceptance of the child

Personal acceptance by parent

Some of the parents reported initial difficulty with acceptance which is evident by statement such as, "I as a parent, found it very difficult when I looked at the condition he was in. But I found myself full of strength because they made me strong from all ends. Right now, I find myself very glad to be with him." Most of parents including fathers expressed love and deep affection for child even with the condition. One father said, "If I won't have enough love for my disabled child how will I expect other people to love him." Complete and unconditional Acceptance of the child was evident through statements such as "We were all surprised to find out that the baby can no longer do anything anymore. But now we have accepted that is what God has given us."

Acceptance by family

Few participants expressed Abandonment and rejection or lack of support from family including spouse, "It is stressful because his father disposed of me, he does not want me. He does not want anything to do with the child". Some of the families faced Difficulty with acceptance of the child's condition which was evident in statement like, "Nobody from my husband's family gives support. Even my mother hasn't accepted, and she doesn't want to hold him." Parents responded to these situations optimistically; this included them assuming that society will continue to behave in this manner and that it would be pointless to attempt to manage their conduct and thoughts. Support and acceptance from many families was identified as a major theme through statements such as, "At home they have accepted this child the way that he is. They are all fond of him. They say to me 'Do not worry, this is the gift that you have been given.'" and "Yes, they have all accepted him at home. He gets support from his siblings, his grandparents, everybody even his father. It’s the same support that I give him.”

Acceptance by society

Gossip, secrecy and misconceptions in society were the commonest themes which came out to be projected from most of the participants. “In our pol (A traditional housing unit) our kids are a disgrace, they hide them. So, for fear of being open, I am also going to hide the baby in the house.” Negative attitudes (i.e. insensitivity, unhelpfulness, and cruelty) from members of community were commonly seen. “When we are at the society garden, people of my age-group would start bragging about their babies, asking each other if their babies can stand and walk. They would talk as if they are actually talking to me, knowing that my child is disabled.” Ignorance and lack of awareness regarding the cerebral palsy and associated disabilities was also found amongst society. However, instances wherein the parents were appreciated for the good care they took of their child were also reported. Some reported having very helpful and cooperative neighbors who did not misbehave with the child and family.

Expectations from society, rehabilitation team and support services

Availability of rehabilitation services

Most participants reported that they consulted several doctors before finally encountering the appropriate specialist. The conclusive diagnosis was sought by them but many of them felt lack of expertise in doctors who have attended them. One of the parents reported, “If the doctor has told me regarding the condition of my child I could have started treatment earlier and saved my child from the suffering”. Difference in opinion from consultants and lack of counseling and explanation of rehabilitation process caused dissatisfaction amongst the parents. “The doctors at this hospital they did not have enough time to explain what is happening to your child. We are seen by different doctors each time.” However, they felt satisfied from the physiotherapist when the child demonstrated improvement after receiving treatment.

The participants reported feeling disappointed when the doctor (physiotherapist) spent a lesser amount of time with the child. One of the parents stated that “The physiotherapist should spend at least 40 minutes with the child during each session, since they had travelled long distances and faced multiple difficulties in bringing the child to physiotherapy centre.” One major issue with the physiotherapy services was found to be the consistency in the care providing person as suggested by, “What upsets me is that the doctors are changed all the time.” They believed that compliance with doctor’s instructions for exercise proved to be better than with the parents’ instructions alone.

Quality of rehabilitation services

Some of the participants perceived that their child’s physiotherapists were well behaved and cooperative and reported that the physiotherapists often provided emotional support as well. The level of satisfaction regarding the skill and experience of the physiotherapist varied among the parents. “They treat him well; they laugh with him and play with him. I feel that they show us love, which is good as it shows us how we should treat our children and how we should listen to them.” A parent reported that “I expect the senior physiotherapist to treat my child, but it is fine if the junior physiotherapist can follow the guidelines given by the senior and treat my child with sincerity.” Participants also reported that occasional consultation on the phone was given as well.

Response to rehabilitation measures

Functional improvement of the child motivated the parents and generated commendable feedback from participants, especially since they were working very hard for the child. “It always feels wonderful to see any new change in her. We know that her condition was poor previously but now things are better.” “He has become better since we started treatment here. Now he has started behaving like a normal child; he has started trying to cry, eat food, walk, and so forth.”

Other support services

Participants reported lack of adequate services such as training centers, schools and financial and instrumental aid and assistance for their children. Few of them have applied for the aid available through various sources but were not provided with the expected results, “My child is 8 years but he doesn’t have a wheelchair. I have registered him so that his name can be on a waiting list. I asked for a wheelchair because he is old now and heavy for me.” They expected the government and non-government organizations to come forward and support them as per their need in customized manner to make their children’s and their life meaningful. They wanted society to understand that by helping the affected child the entire family would be helped.

DISCUSSION

A wide range of problems were uncovered during the interview sessions with the parents. Awareness related to the cerebral palsy: its effects, course, treatment and anticipated outcomes; available various rehabilitative measures and legislative rights as well as aids in the parents was found to be varying. Majority reported average knowledge regarding the cerebral palsy and the legislative and humanitarian rights of the child but were having satisfactory knowledge regarding various treatment options especially physiotherapy. Similar findings were also found in two studies previously conducted in Gujarat.[25,26]

Caring for the child created difficulty in maintaining social relationships which was also reported in a study by Davis et al conducted in Melbourne.[27] In the same study an adverse effect on marital relationship was reported, but this was not the case in present study. Possible explanations for this could be greater availability of family support in Indian culture, which improved the levels of acceptance of the diagnosis by parents thus leading better co-operation in rehabilitation. Mixed responses were experienced by the participants from society; while in some cases the society neglected the child, raised several questions, and made adverse comments, in other cases neighbors provided excellent support to parents in caring for the child. In a qualitative study conducted by Neely-Barnes et al. with parents of children with autism, CP, sickle cell disease, and Down's syndrome, several instances of discrimination from society and family were reported, towards both the child and the parent.[28]

The participants experienced various physical, psychological and financial problems, such as aches and pains, sleep disturbances, emotional problems, stress, worry as a result of stress from caring for the child while observing no improvement in the child's status. Similar findings were observed in UK by Gallagher S et al; in Iran by Sajedi F et al; in Canada by Brehaut JC et al, Raina P et al and Lach et al; in Australia by Davis et al, in India by Diwan SJ et al, Nimbalker et al and Ramanandi VH et al.[2,5,14,17,25,27,29-31] Caregiving demands contributed directly to both the psychological and the physical health of the caregivers. Behavioral issues of a child with a disability were found to influence parents' psychological health. Some of the participants had to leave their jobs as a result of having to care for the child. This caused a great financial burden for them. One common concern experienced by all of the participants stressed on the future of the child a similar finding was observed in the study by Heaman, in which the most common stressor reported by mothers and fathers was a concern about the child's future.[33]

Few more aspects uncovered with this study is lack of detailed counseling and explanation of rehabilitation process by consultants as well as rehabilitation personnel, amount of time a physiotherapist spends with the child, the consistency in the care providing person and lack of support from Government and NGOs.

The general consensus among participants was that the availability of health care professionals, and other support services, for children affected with CP was inadequate. They expect the government and non-government organizations to come forward and support them as per their need in customized manner so that individuals problems are addressed comprehensively. Similar was reported in the study done in parents of cerebral palsy children residing in Gujarat and attending tertiary care hospital.[5,25]

CONCLUSION

A wide range of experiences were described by the parents of children with CP. Common themes such as disturbed social relationships, health problems, financial problems, worries about future of the child, need for more support services, and lack of adequate number of trained physiotherapists were experienced by the parents. While planning interventions for the child, it is important for rehabilitation specialist to consider focusing on the developmental and "technical" aspects of the services that are offered to children with cerebral palsy while other issues such as behavioral issues of child, physical and the psychological health of caregivers, influence of social support, family functioning etc should also not be ignored. Studies like this can provide valuable information for improving depth and quality of rehabilitation services by a physiotherapist through a family centered care program for children with CP.

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