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ORIGINAL PAPER

Psychosocial Challenges for Parents of Children with Cerebral Palsy: A Qualitative Study

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Abstract Care of a child with cerebral palsy is a source of tension and struggle for parents and causes many problems in meeting the child's needs. Therefore, this study was performed to explore the experiences of parents who have children with cerebral palsy. This qualitative study was conducted in 2011–2012 using content analysis through purposeful sampling and by participation of 17 Iranian parents (27–59 years old) of children with cerebral palsy who were referred to the rehabilitation centers in Tehran. The data were gathered by an in-depth semi-structured interview. All of the interviews were transcribed and analyzed inductively. The content analysis revealed four subcategories, "inadequate facilities and services," "unsupportive interactions," "limitation of parents' social relations," and "social seclusion of the child and parent," in the category of social challenges, and three subcategories, "intrapersonal conflicts," "being worried," and "sense of loneliness," in the category of psychoemotional challenges. Caring for a child with cerebral palsy exposes the parents to challenges, some of which are related to the nature of the child's disease, and some are due to a shortage of facilities and lack of attention to the parents' needs. Therefore, to promote the parents' health and provide better care services to the afflicted child, it is important to recognize the parents' problems and remove such obstacles.

Keywords Children · Cerebral palsy · Parents · Psychosocial challenges · Content analysis

Introduction

Cerebral palsy, the most common cause of motor disability in children, is a chronic condition and developmental disorder with some degree of movement and posture dysfunction (Richards and Malouin 2013; Yeargin-Allsopp et al. 2008). The estimated prevalence of cerebral palsy is 2.11/1000 live births (Oskoui et al. 2013). Many children with cerebral palsy experience sensory, communicative, and intellectual impairments; have limitations with self-care; and require specialized care (Raina et al. 2005). Long-term dependence on the parent and the child's need for special care services throughout development imposes different roles for the parents. This also provides the parents with challenging responsibilities and care management experiences, especially for mothers who must provide constant and exclusive care, as a result of which, they fail to take care of themselves, their children, and other family members (Mendenhall and Mount 2011; Tsai and Wang 2009).

Acts 5 and 23 of the *Convention on the Rights of the Child*, which was approved by the general assembly of the United Nations (1989), placed an emphasis on the rights of children with disabilities, attention to these rights, the parents' responsibilities, and provisions for appropriate facilities for children with disabilities and their parents. However, ignoring these issues and concerns can create problems for the parents of children with disabilities. Parents of children

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with chronic disorders experience social problems, such as a lack of or poor access to health care services, school services, or family support, in addition to experiencing a continual struggle to include their children in the school and community, financial strain, a lack of public awareness about the child's illness, and stigma (Ambikile and Outwater 2012; Klassen et al. 2012; Resch et al. 2010).

Knox (2008) argued that the realities of cerebral palsy, as well as the worries and expectations of parents of children with cerebral palsy, were understudied. Although the voice and interpretations of those that are the focus of study can help us to understand the phenomenon of interest (Polit and Beck 2006), there are few studies that have explored the problems of parents of children with cerebral palsy based on their thoughts, perceptions, and experiences in Iran. Previous studies with similar groups of Iranian parents have assessed the parents' mental health and quality of life using a quantitative approach. These studies found that mothers of children with cerebral palsy showed a high prevalence of depression (70 %; Kazerani 2003), high stress levels (Sadeghi 2004), and a significant relationship between their quality of life and the child's type of cerebral palsy (Sajedi 2008). Moreover, parents of these children had higher depression levels and a lower quality of life compared with parents of healthy children (Ahmadizadeh 2012; Khayatzadeh 2009). Nevertheless, in the Netherlands, more than half of the parents of children with cerebral palsy that were examined by Okurowska-Zawada et al. (2011) showed a good quality of life and reported satisfaction with their health. These findings contrast those reported in Iranian parents of children with cerebral palsy, which suggest the likely presence of problems that ultimately decrease their health and quality of life. Hence because of the importance of the parents' role in supporting and caring for their afflicted children, it is necessary to pay attention to the parents' needs and challenges. Therefore, we conducted this qualitative study (in 2011–2012) to explain the problems that parents of children with cerebral palsy experience when caring for their children.

Method

Participants

The participants were selected from parents who were currently receiving services for their children at outpatient rehabilitation centers in Tehran. The inclusion criteria included parents who were living with their partner (wife or husband) and had experience with caring for their child at home. The eligible parents were introduced to the researcher by therapists. The children of these parents were in different levels of cerebral palsy, and the severity of their movement disorders was previously assessed by occupational therapists, according to the Gross Motor Function Classification System (Palisano et al. 2007).

Using purposive sampling, which was continued until the data were saturated, we interviewed 17 parents of children with cerebral palsy (12 mothers and 5 fathers from 15 families). The parents were 27–59 years old ($M = 41$, $SD = 9.85$), and their level of education was as follows: less than high school = 3 (17.6 %), high school graduate = 7 (41.2 %), and beyond high school = 7 (41.2 %). All fathers had jobs, 10 mothers were housewives, and 2 mothers had part-time jobs. Sixteen participants had one child with cerebral palsy, and 1 mother had 2 children with cerebral palsy. Two families (13.4 %) had more than 2 children; 6 families (40 %) had 2 children, and 7 families (46/6 %) had 1 child. The parents had experience with caring for children with cerebral palsy who were 2.5–16 years old ($M = 7.75$, $SD = 3.53$) with different levels of cerebral palsy, varying from mild to severe (mild 31.25 %, n = 5; moderate 25 %, n = 4; severe 43.75 %, n = 7). Most of the children (68.75 %, n = 11) suffered from problems related to cerebral palsy including intellectual, visual, and hearing impairments; communication and speech difficulties; and seizures.

Procedure

Participants were given an explanation regarding the study purpose and methods. The participants provided written informed consent, and they were informed of their right to anonymity and could withdraw from the study at any time.

The data were collected with in-depth semi-structured conducted in Persian. The first author of this study conducted the interviews in a quiet place without distractions, which included rehabilitation centers and the participant's home (in three cases), according to an agreement with the parents. The interviews were recorded, except for those with 2 mothers who did not consent to the recording and were briefly noted during the interview. The short notes were completed immediately after the interview, and the interviewee and first author confirmed the correctness of the interviewer's notes. The interview durations varied from 30 to 60 min, and each parent was interviewed in 1 or 2 sessions. Each interview began with the following questions: "What problems did you encounter after your child's diagnosis of cerebral palsy?," "What problems do you have when caring for your child?," "What difficulties do you have in the community?," and "How has your child's condition affected you?," The interviews continued with questions that were revealed in the interactions between the interviewer and the interviewee. Moreover, in order to gain deeper information, some heuristic questions were asked, such as, "Explain more" or "What do you mean exactly?"

Data Analysis

This study was carried out with a qualitative approach by content analysis. Content analysis is widely used in qualitative research and is used for phenomena in which the available knowledge is fragmented. This is an appropriate method for obtaining condensed and broad descriptions of a phenomenon (Elo and Kyngas 2008; Hsieh and Shannon 2005).

The method of Graneheim and Lundman (2004) was used in the present study. This method has four stages: choosing a unit of analysis (whole interviews); detecting the meaning units and referring to a keyword or phrase (a code in relation to context); condensation, or the process of shortening with preserving the core; and abstraction, or descriptions and interpretations on a higher logical level and creation of categories.

The audio files were transcribed verbatim for the data analysis. The transcripts were then read several times and their meaning units were specified and condensed with a description close to the text. After that, a list of codes was provided and reviewed semantically. Then, by determining the similarities and differences in the meanings, similar codes were assigned at a more abstract level using a reduction and induction method. Data analyses were performed by the first author, and all codes and categories were confirmed with the research team during periodic meetings; there was a consensus among the team regarding the data analysis. Therefore, the researchers defined some acceptable subcategories and categories.

Member check, peer check, and external check were used for the sake of trustworthiness. In order to achieve a better understanding of the participants' comments, the findings were given to some participants to confirm the fitness of the data labeling with the participants' experiences (member check). In addition, some of the transcripts were reviewed by faculty members who were familiar with qualitative research (peer check). Dependability was established through an audit trail by two experts who examined the data documentation, analysis methods, and the findings.

We also attempted to increase the credibility of the data by sampling from state and private centers, different demographic categories, and children with different levels of cerebral palsy. In addition, we increased the number of interviews with the participants to improve credibility.

Results

Based on the parents' experiences, we identified two main categories: social challenges and psychoemotional challenges, and seven subcategories (Table 1).

Table 1 Emerged categories and subcategories

Main categories	Subcategories
Social challenges	Inadequate facilities and services
	Unsupportive interactions
	Limitation of parents' social relations
	Social seclusion of the child and parent
Psychoemotional challenges	Intrapersonal conflicts
	Being worried
	Sense of loneliness

Social Challenges

This category indicates the various problems that parents experienced with facilities and services, the social environment, and others' behavior and actions towards the parents. The subcategories includes in adequate Facilities and Services, Unsupportive Interactions, Limitation of Parents' Social Relations, and Social Seclusion of the Child and Parent. These subcategories are further defined below.

Inadequate Facilities and Services

This indicates a shortage of social welfare and therapeutic services. The social welfare shortage includes a lack of daycare centers for the child, lack of respite care services for the parents, wheelchair obstacles in some public and private places (stairs, entrances without ramps, no elevator, uneven surfaces), problems with civil transportation, and a lack of appropriate toilets for children with disabilities in medical and recreational centers or other public places. Regarding the need for a daycare center so that the mother can pay more attention to her other children, one mother stated:

> I wish there were a special place in the society in which we could leave these children during the day; I may ignore my other children for taking care of this child…

When considering the differences in the toilets used in Iran and some Middle East countries, and the lack of appropriate toilets for children with disabilities, the mother of a 5-year-old child stated:

> With the pain I have in my joints, I can't sit the child on the usual toilets. There is just one toilet similar to those toilets used in The European countries; however, it is too big so that my child completely falls in it.

The shortage of therapeutic services includes limited access to some medical facilities, limited working hours in state rehabilitation centers, long waiting lists, a shortages of skilled therapists, and a lack of financial support. These factors forced some parents, even those with financial problems, to use private rehabilitation centers with more expensive services. Additionally, insurance often does not cover all rehabilitation services. However, the parents with financial problems attempted to reduce their costs with fewer referrals to private centers, but that this adversely affected the child's health. The financial support provided by supporting organizations, which allocate support based on a family's needs and the severity of the child's disability, barely covers some of the parents' expenses. Therefore, the parents stated that financial support is the most important factor for the promotion and maintenance of their child's health. Regarding the shortage of financial and service supports, one mother stated:

> Insurance doesn't accept these children at all. It doesn't accept some of their medications at all. These expenses are really difficult and burdensome.

A father also declared:

> Because of the expenses, we take the child for occupational therapy once a week, while the child's need is more than that.

Unsupportive Interactions

This subcategory includes sympathy, regret, questioning and curiosity, inappropriate comments, a lack of understanding for the parents' troubles, and little or no acknowledgement of these troubles by relatives and other community members. Some parents mentioned that the sympathies and queries result from a lack of awareness of the child's disease and improper interactions. The mother of a 3-year-old child mentioned:

> People ask irrelevant questions: 'Why do you carry the child with yourself all the time, you get tired'. They say this due to sympathy and because of their unawareness. These words force me to say that my child is tired.

Another experience of the parents was stigma that appeared in the form of unusual looks, judging the parents by blaming, and reprimanding them. Regarding stigma, one of the mothers stated:

> They look at you in a way that (stating with sorrow) as if you have the misfortune of the world; meaningful looks are difficult to bear.

Another mother said:

> My relatives said to me that surely you have not been attentive during the pregnancy. Unfortunately, this is the mother who is always considered guilty.

Limitation of the Parents' Social Relations

Providing constant care for the afflicted child, the child's movement impairments, his or her care dependency, the parents' time spent engaging in the care and treatment of the afflicted child, and a lack of trained individuals that can provide temporary care for the child restricts the parents' social interactions and relationships (especially for the mothers who have the primary responsibility of taking care of the child). Sometimes, because of others' awareness of the child's movement impairments and care problems, the parents are not invited to or informed of family events and ceremonies. As a result, they spend less time with their relatives and others in the community, which cause a separation from others. When it is necessary for the parents to attend a ceremony or event (family or recreational), one of the parents will not attend the event to care for the child. About the constant care for the child, a mother declared:

> The child is always with me. What can I do; my biggest problem is that there is nobody to keep the child for me to have a time for myself. I really feel that there is a chain on my hands and feet. With the child with me, I can do nothing.

Social Seclusion of the Child and Parent

Because of physical limitations, many of these children are deprived of outdoor activities. A lack of acceptance for the child's condition, for communicating with other children, the presence of environmental obstacles, and a lack of necessary structures for his or her presence in different sporting and recreational spaces, a lack of well-trained tutors for training the child in public sporting settings add to the child's limitations and separation from his or her peers, and force the parents to stay home more often to take care of the child. Sometimes, to hide the child's physical and mental problems in public, and to avoid undesirable interactions with people, the parents reduce their contact and communication with others by avoiding public places and staying home more frequently. A mother said:

> We always put the child at home; his father is at home and I go shopping. We don't take the child to places with stairs or we ourselves don't go there. Are there any facilities outside for us to take the child there?

One of the mothers with a 6-year-old child mentioned:

> I always sit somewhere far from the view of others. I feel my mother-in-law and sister–in-law don't want me to be in their group because of my child who is not normal.

Psychoemotional Challenges

This category refers to the parents' feelings and emotions about having a child with cerebral palsy, taking care of him or her in the present and future, and about their own condition as a caregiver. Three subcategories in this category include Intrapersonal Conflicts, Being Worried, and a Sense of Loneliness.

Intrapersonal Conflicts

This subcategory involves tension and negative feelings, such as feeling sinful, twinge conscience, feeling different than others, a lack of self-esteem, feeling culpable, feeling jealousy or shame, regret for losing time and life experiences, feeling of death, dislike towards the child and the wish of his or her non-existence, feeling sorrow when watching other children, and comparing healthy children with the afflicted child. These feelings are especially apparent when the parents feel that they have no control over their child's health problems and have a disabled and depended child. A mother stated in this regard:

> Maybe I have done something wrong sometime; perhaps I have committed sins and God is taking revenge. I have a twinge conscience.

In some cases, the parents may also consider themselves as culpable. A 59-year-old father stated:

> Of course, I know myself culpable; I shouldn't have this child at that age.

When encountering the disease and treatment, the distress and damage to the child during the treatment (especially in the early years after the disease diagnosis) and a lack of his or her cooperation with treatment, produces tension in the parents that manifests as nervous pressure. One of the fathers said:

> You don't believe; those days I was under great nervous pressure for the disability of the child.

Being Worried

Parents' constant worries include the child's health and education, how to maintain and provide care for the child in the future. They did not expect their healthy children or relatives to care for their afflicted child in future. Of course, the dependency level of an afflicted child is associated with the intensity of the parents' concern, so that parents of an afflicted child without mental problems and with low physical problems experience less worries. A father stated:

> When we died tomorrow, who will take care of this child; her brother or sister can't. If she could walk some steps and almost do her daily living activities, we would have less worry.

Sense of Loneliness

Others' avoidance and ignorance of the parents' needs for communication, the absence of a guide for child care in critical situations, the feeling of being deprived of support in caring for and keeping the child all contribute to a "sense of loneliness," especially for parents of children with severe cerebral palsy. In some cases, the parents experienced a sense of helplessness by stating they carry burdens on their shoulders, and nobody can help. A mother said:

> Nobody has supported by now, never, never. Neither the organization, nor the relatives have supported. There's nobody to take the child's hands and walk with her for a few steps. Or there is no staff to help with the exercises of the child instead of sitting. Nobody helped us.

Others' providing caring attention to the child and having a sense of the importance for the child's existence can decrease the parents' sense of loneliness. One mother stated:

> When I see my family is very sensitive to my baby, I become much more hopeful, more confident, and think that this isn't just me who worries about her, others also share and are sensitive on her.

Discussion

The findings of this study showed that the parents of children with cerebral palsy experienced unique psychosocial challenges related to the child's care and health problems. A lack of financial support, limited access to medical services, limited welfare facilities for their social presence and their child were problems that most of the parents in the present study experienced. A lack of financial support from insurance organizations for the afflicted child's treatment further increased the parents' medical expenses. Sen and Yurtsever (2007) found that the economic load of the treatment, care, and training for the afflicted child were mostly experienced by families who did not enjoy sufficient financial support. Several studies indicated the feeling of a lack of support in most parents was due to limited access to services, long waiting lists, increasing treatment expenses that exceed the family income, a lack of appropriate sanitary facilities (such as toilets), and a disparity between the parents' needs and social resources (Ambikile and Outwater 2012; Davis et al. 2010; Lutenbacher et al. 2005; Raman et al. 2010; Resch et al. 2010). In our study, parents described another problem, which was a lack of formal services for temporary childcare as an opportunity for preventing fatigue, refreshing, and performing daily activities and routines. This deficiency was more common for parents who did not have informal support from their relatives and friends. Palisano et al. (2009) found that the parents of children with movement disorders had needs for relief, temporary rest, recreation, and a temporary place for keeping the child. The study by Yantzi et al. (2007) also indicated that mothers faced social problems such as limited access to an alternative and trained caregiver; therefore, they sought help from their friends or family members when leaving the house.

In this study, parents, and especially by mothers, described unsupportive interactions and stigma experienced as reproach and being judged or considered culpable by relatives. Other researchers, especially those in the Asian countries, reported similar findings that support our present findings: mothers reproached by family members, including husbands, scrutinizing and sorrowful looks, a lack of social understanding for individuals with disabilities, in the form of regret and sympathy were undesirable experiences, whereas natural behavior towards the disabled child could help generate a sense of equality with other healthy children (Huang et al. 2011; Raman et al. 2010; Whittingham et al. 2011). Park et al. (2009) found that Korean families of children with a chronic disease faced more negative social responses as compared to their counterparts in Western countries. Furthermore, these researchers suggested that supportive programs should be designed to help improve understanding of afflicted children and their families.

A lack of acceptance for the afflicted child in the community by healthy peers, a shortage of environmental facilities, public facilities inadequate for people with disabilities, coercion of the parents for staying at home, and keeping the afflicted child were some of the social problems these parents faced. According to the International Classification of Function, Health and Disability (ICFHD), environmental factors (physical, social, and cultural) play important roles in the social modeling of disabled individuals in the form of their involvement at home, school, broader environments, and different life situations (Lawlor et al. 2006; Rosenbaum and Stewart 2004). In addition, Lawlor et al. (2006) argued that the obstacles for the social presence of a child with cerebral palsy in England were implied in the themes of activity and movement (unleveled surfaces in the physical environment, the dependence of the afflicted child on the adults, difficulty in access to public transportation, a lack of parking facilities, a lack of an elevator, and improper paths for wheelchairs), individual attitudes (in the form of still and sympathetic looks) and socially institutionalized attitudes. Generally, the deficiencies in facilities that impede the child's social presence and his or her greater dependence on adults increase the parents' supportive and caring engagements for their child. Dixon (2011) found a lack of support from public services and stigma were the main reasons for the isolation of families with children who have disabilities. In this study, the parents' social seclusion could have resulted from the parents experiencing unpleasant social interactions (inappropriate relationship with parents and low acceptance of children in the community). These results are compatible with those of Nelson (2002), who stated that a mothers' social separation (physical and psychological) was due to therapeutic diets, a high sense of responsibility for the child's well-being, and a lack of understanding for the child's acceptance by others. The parents' separation from others, the way others think about the ability of managing the child, and being ashamed of his or her own performance could contribute to the parents experiencing a social stigma (Pullmann et al. 2010). The above findings, along with the results of the present study, represent social ignorance towards children with disabilities and their parents.

The results of this study indicated the intrapersonal conflicts for parents in different stages of childcare. Having a disabled child results in emotional excitement, a low level of tolerance, a willingness to escape, and wide changes in all aspects of the family's life (Shakoor et al. 2009). Huang et al. (2011) found that feelings of guilt, helpless, hopelessness, sorrow, anger, and self-blame were experienced by the mothers who were exposed to their child's disability. Of course, when the parents receive more support, the negative effect of a child's disability on the parents' mental health decreases (Ha et al. 2011).

In this study, the parents had considerable worries about their child, but their worries decreased with improvements in the child's therapy outcomes and quality of life. The parents who found themselves successful in improving the child's ability and independence felt less worry. The child's age, type of cerebral palsy, and level of disability influence the extent of the parents' concerns (Knox 2008). Ambikile and Outwater (2012) also found that the parents of children with disability experienced inner pain and worries about the present, in addition to the child's future. Huang et al. (2011) argued that Taiwanese mothers experienced modes of being concerned when faced with challenges and obstacles in caring for their child. One of the mothers' concerns was the marginalization of disabled children due to a lack of attention to the child's rights and physical security in society and schools. The results of the present study showed that parents did not expect their healthy children or relatives to care for their afflicted child in future. Meanwhile, Coffey (2006) argued that the parents' worries were due to their doubts about the ability of brothers and sisters to care for the child in the future. Sometimes, a parent's worry about a child's health in the future causes the parent to make more of an effort in promoting the child's health. Of course, resources such as emotional support, financial ability, physical help, access to services and social supports, attention from policy makers in the health field to the improvement of environment and appropriate transportation structures, and greater consideration for psychological and social work services in the rehabilitation centers, can decrease parents' worries, and improve their quality of life, family well-being, and the quality of parenting (Armstrong et al. 2005; Davis et al. 2010; Khayatzadeh 2009; McCubin and Hung 1989).

The sense of loneliness in this study, especially in the mothers, showed the lack of a social support network in addressing the parents' needs. Barbosa et al. (2008) found that the mothers of children with disabilities experienced a sense of helplessness when they were unable to change their situation. Therefore, based on the results of the present study and previous studies, a lack of provision for the parents' emotional and practical needs when caring for the child creates a sense of loneliness. Emotional loneliness (an emotional state of feeling isolated) has negative consequences on an individual's physical health (Bogaerts 2006).

Social resources and emotional security could help to decrease the parents' stress and worries and improve their quality of life. However, the findings of the present study showed that parents endured many social and emotional problems in living with their children because of the lack of social facilities and social support networks.

Given the nature of qualitative studies and the small number of participants, our findings cannot be generalized to a larger population; however, all concepts in this research reached saturation and nearly provided a comprehensive perception of socio-emotional problems among Iranian parents who have a child with cerebral palsy. Therefore, it is recommended that further studies be conducted to explore parent strategies for confronting the social and emotional challenges.

According to our findings, when taking care of their children, the parents need more societal conveniences, comprehensive health care facilities, and critically rehabilitation-medical services. However, organizing a facilitating system and providing integrated support to parents would play a critical role in promoting both the child's and the parents' health. Furthermore, it is necessary that decision makers provide more supportive resources for these parents to be able to effectively manage themselves and the afflicted child's situations.

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