

ORIGINAL ARTICLE

## Children with learning disabilities: A phenomenological study of the lived experiences of Iranian mothers

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### Abstract

Nursing as a family-oriented profession involves supporting mothers of children with learning disabilities to gain an awareness of their role. However, few studies have explored the whole experience of such mothers. This study embarks on an understanding of lived experiences of Iranian mothers who have children with learning disabilities. A qualitative approach was adopted using the phenomenology of semi-structured interviews carried out with six Iranian mothers whose children attended a special school in Tehran. The data were analysed in line with van Manen's suggestions. Two main themes were abstracted; *being the centre of stress circles* and *being in the midst of life and death*. Themes include care management challenges for self and child, experiencing through helplessness and hopefulness and experiencing self devote and self neglect. Overall, a majority of mothers experienced a stressful life. The study concludes that Iranian mothers' lived experience of having children with learning disabilities can be likened to the constant swing of a pendulum between two polarities of positive and negative feelings. This knowledge can provide an heuristic to help health staff guide mothers in adjusting to their children who have learning disabilities.

**Key words:** *Phenomenology, Iranian mothers, learning disability, child*

### Introduction

*The impact of having a child with learning disability in a family*

Learning disability, termed "mental retardation, intellectual disability, developmental disability, mental handicap" in ICD-10, is defined as significantly below average general intellectual functioning (Berney, 2006; Brown, 2005) accompanied by deficits or impairments in adaptive behaviour, and with an onset in childhood (Wilkinson & Bhate, 2006). To have a child with learning disability leads to many changes in the lifestyle of the whole family. Identification and acceptance of learning disabilities are difficult processes, which have great qualitative and quantitative influences on family lifestyle, and promoting the child's optimal development. They require adaptation by all family members and support from each of them (Roach & Orsmand, 1999).

Research studies (Roach & Orsmand, 1999; Sisk, 2000; Lai & Mackenzie, 2002; Ong, Chandran & Peng, 2005) have indicated that parents of children with disabilities experience a greater level of stress than do parents of children without disabilities. Physiologically and psychologically, they have to devote a great deal of their time, energy and patience to taking care of and training their children in day-to-day life skills. They have to come into terms with the sense of loss of the expected "normal" child, accept the reality of having a "less-than-perfect" child, integrate the child into the family, and take on the lifelong process of rearing a child who is "different". The long-term uncertainty of the child's capabilities, future health, growth, and ultimate level of functioning and the family's ability to meet the child's needs and deal with their behavioural problems are factors which add further to parents' psychological stress and their effect on

self-perception and family functions (Hatice & Dokuz, 2006; Raina, O'Donnell & Rosenbaum, 2005). Parents of children with disabilities report experiencing chronic sadness, reduced self-esteem, and an increased level of depression. They are less optimistic and self-efficacious and more negative and self-blaming (Lai & Mackenzie, 2002). Past qualitative studies have yielded a genuine understanding of challenges faced by parents with children who are sick or have disabilities. This study intends to extend the literature on how mothers of children with learning disability view and manage their circumstances and acknowledges the context and culture within which their experiences occur. As such, this study is valuable to extend our understanding of the commonalities and differences between diverse cultural experiences of mothers who are parenting children with learning disabilities. Furthermore, professional health workers do not always provide adequate information about learning disability and rarely do they give enough printed materials or make appropriate referrals to parent support groups (Poehlmann, Clements, Abbeduto & Farsad, 2005; Skotko & Bedia, 2005). In addition, identifying health problems in the family and the subsequent lifestyle changes required are essential if appropriate services are to be provided. Identifying problems and using that information to plan the child's care can provide great benefits. However, this in turn relies on health staff's perception of the experiences of mothers who have children with learning disabilities. Thus, it is critical to explore the experiences of the aforementioned mothers and develop a holistic intervention approach for them and their families so that effective mothering is achieved.

### **Iranian background**

In Iran, formal educational support for families who have pre-school and school age children with learning disabilities is limited. Mothers are usually the primary caregivers; the extra burden of caring, rearing and educating the child usually falls on them. They have to seek actively the resources for supporting and helping their children. There are no school nurses in exceptional schools and there are insufficient consultation and counselling services for the children with learning disabilities and their mothers. Consequently, all the families who have a child with learning disability keep their child at home, and without any effective social service infrastructure to help and support them. In effect, they are part of the social system but without any supportive or care plan provision. Hence, studies of lived experiences of the mothers who have children with learning disabilities could be of great benefit to

health professionals and other sectors within the social system enabling them to provide effective support. Therefore, studies that focus on long-term learning disabilities' outcomes and the required adjustments are needed. The purpose of this study was to understand Iranian mothers' lived experiences of having children with learning disabilities.

### **Method**

The study sought to address the lived experiences of Iranian mothers who have children with learning disabilities by a qualitative research design with phenomenology as the underlying theoretical framework. van Manen's (2001) approach to phenomenological research was used to develop appropriate techniques for the research design and for analysis. The approach is founded on an understanding of consciousness as always embodied and never removed from our lived experiences. As embodied beings, we know the world through shared understandings, making it an inter-subjective experience: We share in the discourse of our culture and society. Thus, what one person experiences might be similar to what others experience because both participate in and interact with the same world (Wilde, 1999). We utilized van Manen's research approach as a guide to new ways of thinking about the mother's experience of living with a child who has learning disability and to enrich reflection during data analysis. The approach for the study can be understood as a hermeneutic phenomenology aimed at illuminating the nature of the mothers' experience of living with a child with learning disability. According to van Manen (2001), the facts of lived experience are always already meaningfully (hermeneutically) experienced and conveyed through language; this is an interpretive process.

### *Data collection*

For data gathering, the semi-structured interview method was used and responses were recorded on audiotape. The main question in the interviews was: "Please describe what is it like to be the mother of a child with learning disability?" Interviews, ranging in duration from 90 to 120 minutes, took place either in the participants' homes or in their children's school. Each participant was allocated a numeric code. All of the interview contents were transcribed, and were then interpreted. We twice interviewed six Iranian mothers who had children with learning disabilities and were being educated at a special school in Tehran. Respondents were interviewed twice to allow them to expand and clarify their descriptions of their experiences, and to help the

researcher to understand the emerging patterns that were developing.

### *Informants*

The six study participants' ages were between 28 and 42 years (mean = 38 years) and all of them were housewives. They were all married and lived together with their husbands. Four mothers had one or two healthy children and one child with a learning disability. Two mothers in the study had only one child with a learning disability. The children with disability were aged between 6 and 12 years (mean = 9 years). Four of them were the first-born child.

### *Data analysis*

The data analysis was processed in line with van Manen's approach as follows:

*The First step.* A holistic approach towards the data was adopted in order to discern both overall and fundamental meanings of the experience. Each interview was condensed to a short understanding of what it was like to be the main caregiver in this chronic (unremitting) situation. Moreover, turning to the nature of lived experience required that I (as the first author) had to examine my own pre-understanding, including my personal experiences of having a brother with learning disability and having to utilise an especial service and my professional experiences as a paediatric nurse over the past two decades. In addition, I paid particular attention to the experience of having a child with learning disability in every day life, such as participating in his day-to-day care and support, and whilst watching television, movies and during conversation with friends.

*The Second step.* This step includes a hermeneutic reflection. Keeping in mind research activities, the selective approach was used to isolate thematic statements. This was done by highlighting phrases and quotes that "stood out" and seemed to be thematic of the experience of mothering. The question asked of the data in this approach was, what does this sentence/meaning unit reveal about the phenomenon, being a mother, in this situation?

*The third step.* A detailed approach was adopted where the researcher interpreted each sentence or meaning unit in a way that was pertinent for the discipline of nursing. The questions were, what does this sentence/meaning unit reveal of the nature of the phenomenon, mothering in this situation, seen from a nursing perspective?

*The fourth step.* This step was to create a mindful and sensitive phenomenological text that could be useful to family care nurses. In this phase, the focus was first on the highlighted data identified during the selective approach. These phrases and quotes were read, re-read, combined, reduced, written and re-written until a satisfying basic structure or essence of what it was like to be a mother in this chronic situation was found. This basic structure was then grouped into themes and sub-themes. Later, meaning units and a detailed approach were considered.

Three steps were taken to ensure the reliability and validity of the gathered data:

1. The preliminary findings were presented to our research colleagues at a seminar in order to attain a collaborative analysis. Transferability refers to external validity. It rests with the audience to judge transferability to similar situations based on the broad description of the findings (Polit & Beck, 2006).
2. An audit trail and evidence that supported interpretations and dependability were provided. Conformability indicates researchers' neutrality, and shows the linkage of the data with the sources and the emergence of the conclusions and interpretations from them.
3. Trustworthiness of data can be established by readers' evaluating the soundness of data gathering and analysis for this study. Accuracy of data (that is to say whether the researcher understood what was said) was confirmed by study participants who discussed on-going interpretations with the researcher. Although all participants were given the opportunity to read their transcripts or summaries, many declined because of lack of interest or poor vision; hence, most interpretations were verified and clarified verbally.

The ultimate goal of this study, therefore, was to grasp the meaning of being a mother who has a child with learning disability, and present the meaning in a way that will affect family nursing. After the steps above had been taken, the researchers believed that the interviews demonstrated validity within the local Iranian culture and context.

### *Ethical issues*

The study was reviewed and permission granted by Tarbiat Modares University. All participants were informed about the purpose and the method of the study. They were informed that participation in the study was voluntary, and they could refuse to

participate or withdraw from the study at any time without any repercussions. The participants were reassured that their responses would be confidential and their identities would not be revealed in research reports or publications. Finally, the participants who agreed to take part in the study were asked to give written consent.

## Results

### *The Iranian mothers' lived experiences*

The mothers' lived experiences could be classified into two main themes; *being the centre of stress circles* (being surrounded by stressful circumstances), and *being in the midst of life and death* (fluctuating between feeling alive and full of hope and being utterly drained and lifeless) and sub-themes that elucidate the variety of meanings of the main themes (see Table I).

#### *Being the centre of stress circles (being surrounded by stressful circumstances)*

In Iranian culture, most mothers' perception of a child with a learning disability is very distinct and especial; so they often referred to the child as "a part of themselves". The child had become such an intrinsic part of their lives that they were thinking about them frequently and consciously. They have to devote a great deal of their time, physical and psychological energy and patience to taking care of and training their child in day-to-day life skills. Consequently, they have experienced a great deal of stress in their lives. In view of the children's high level of dependency, assisting the disabled child to perform routine activities of daily living such as eating, using the toilet, as well as helping them with their schoolwork placed heavy physical, psychological, and social demands on the participants. Almost all mothers indicated that they carry out all the tasks on their own and without any assistance, which was difficult and stressful for them. For example, one of the mothers stated:

... my son is 9 years old now, but I feel I have endured 90 years of physical and psychological

pressure ... I don't think anybody can do anything for us ... I feel I am semi-depressed because having a disabled child is very hard and painful ... I feel deeply sad, I'm depressed ... I am unable to run away from it, nor able to leave it.

Hence, the sub-theme was *Care management challenges for self and child*. Participants described that they have encountered problems with respect to taking care of their children, communicating with others, and they had anxieties concerning the child's uncertain future. Several mothers said that they are unable to manage their child's health and provide adequate training for routine life skills. One of the mothers stated:

I take care of him now, do everything for him, but I cannot take care of him when he is 20 years old ... I don't know what I should do ... how can I make him independent? He is twelve years old but he cannot go to the toilet and bath himself independently, I have to assist him on my own. Some people taunt me and this is stressful for me.

Participants described their experiences of how they had attempted to develop their communication with their disabled children and the means of managing their sensitivities with respect to the child's conduct in public and others' behaviour towards them, and how they had utilized problem-solving mechanisms. A 37-year-old tearful mother stated, "as a direct result of our sensitivities, we are holding back from mixing with people and socializing with friends and family alike". Participants indicated that they were concerned about their child's conduct in public, and how to manage it, and resorted to limiting their social interactions. For example, another respondent, whilst crying, stated:

I am very sensitive to others' behaviour and comments aimed at my child. I cannot help it. I always focus on what they do and what they say. Therefore, I always stay at home because people don't understand our child, and we hardly have any social relationships.

Most mothers described that they experienced anxiety regarding the child's uncertain prospects including issues such as their status in future, both short-term and long-term. Immediate worries included a child's school placement and his state of health. Looking further ahead, the mothers' major concerns are the child's ability to care for themselves and issues such as getting married, having an occupation and becoming independent, the degree of child's willpower, and who would be responsible

Table I. The main themes and sub-themes of Iranian mothers lived experiences.

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**Being the centre of stress circles**  
Care management challenges for self and her child

**Being in the midst of life and death**  
Experiencing through helplessness and hopefulness  
Experiencing self devote and self-neglect

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for their care after their mother's death. As one mother said:

I am afraid I would still have to take her along with me when I am old. Sometimes I come across mothers who are very old but still have to take along with them a grown-up adult of this kind . . . Immediately I think about myself and I feel tears in my eyes . . . It seems that I am looking at my own future.

Some mothers even hoped their child would die before they did, and worried about who would care for their child when they and their husband died. It appears that mothers in this situation are walking a tight rope fluctuating between stress and uncertainty. One of the important factors in stress management is an effective care plan for oneself and the child. However, the findings showed that most mothers did not have a clear plan of how to balance their own needs and the care of their children, which resulted in constant stress and negative psychological feelings. For example, one 37-year-old mother stated, "I do not have a special plan for health promotion and quality of life for my child. I don't know what I should do for my disabled child . . . and that is why I don't feel happy, I feel sad for my son". In fact, they were unable to solve or manage the problems that arose from their situations and experienced a lack of control on how to ensure their children's futures. This realistic perception of their limitations resulted in negative psychological outlooks and emotional states for the majority of the mothers.

*Being in the midst of life and death (fluctuating between feeling alive and full of hope and being utterly drained and lifeless)*

The experience of living with a child with a disability was like a pendulum that swung back and forth between life and death. Participants did not identify learning disability as positive or negative; instead, they told stories about how it was both positive and negative, depending on the situation or the problems it caused. The mothers felt alive and full of hope when their children were loved, respected and not despised by others, as well as when they felt their child was a gift of god, and were supported by others too.

In the Iranian culture, parents believe that the baby is a beautiful "blessing and a gift". God supports the new parents in psychological, emotional and economic terms. There is a belief that the parents of a child with learning disability are likely to experience significantly higher levels of God's attention than are parents of children without disabilities. Beliefs within the Iranian culture are that one of God's most

important tests is illness or any disability of a child; it has been "God's will, the child has been sent to test us, and the child is a life blessing". These beliefs help mothers to accept their child with learning disability. Some mothers described how their religious beliefs helped them come to terms with the disability of the child. For example, "whatever happens, it is the will of God. It has been my fate. I've accepted the birth of my child easily and believe that it has been God's wish to test me". Some mothers described that "God would reward them in life after death for their patience and in this life too". In fact, the presence of the child was generally considered as a special blessing from God. In other words, mothers tried to see the disabled child as a "special gift" from God, so they perceived this phenomenon as "special attention" from God or as God's favour. Thus, they could accept their children and their difficulties and devoted themselves totally to attending to their needs and took pleasure from it as they believed that the disabled child was a gift of God and it is God's wish to test them. A 29-year-old mother said:

My son is an indication of God's trust. I give you 'a broken cup' and tell you please keep it for me. You have to take care of it to avoid it reaching the breaking point . . . Now, Kasra is our 'broken cup' and we should take care of him so that his problems are not exasperated. God gave us a disabled child and we are content with our God . . . I submit to God's will. God always knows best and will send good deeds for us. There is always a hidden wisdom and I am always placing my trust in him. I tell myself that he must be testing me here and would be rewarding me in the next life.

Another mother stated, "This disabled child is God's gift. It has protected us from misfortunes and has endowed our lives with more blessing". In addition, when a mother was supported by her husband or others, she felt alive and hopeful. A 41-year-old mother described that, "When my husband understands me, this helps me to calm down. I become happy and enjoy my life more and it increases my life satisfaction". Some mothers described acceptance of, and attention to, the child by others as the basis of their tranquillity. One of the mothers stated that:

. . . in the cold days of winter when my son and I came back home for lunch, we saw neighbours bringing us lunch . . . or another time they defended him against the taunts of others or when the child is loved and accepted, and is contented . . . at that moment I feel relaxed and at peace with myself.

The first sub-theme was *experiencing through helplessness and hopefulness*. Furthermore, both religious beliefs and the perceived support of others resulted in mothers feeling alive and hopeful. In contrast, when they did not receive effective support from husbands, relatives, friends, professional health workers and school staff it led to loneliness, having a painful, stressful life, and feelings of helplessness and desperation. In addition, fathers do not play an effective role in care of the child; they work long hours and mothers have to care for their children. One of the mothers stated, "My husband doesn't take care of our son, he seldom asks me about my problems with the child. I feel alone. I'm helpless". One of the other mothers stated:

I go through a lot of a trouble for my son to speak one word. It has been so hard for ten years; this is a lifetime [expressing herself with stress] ... when he says 'hello' to his grandfather, he doesn't pay any attention to him or when my son could not speak well, his grandfather says I should beat him so that he understands how he must speak ... This kind of behaviour is very painful for me, as though I have been stabbed in my heart.

The second sub-theme was *experiencing self devote and self-neglect*. Our findings indicate that parents usually keep their disabled child at home. This is because first, there is a very limited social services support available for their family, and second, mothers take care of their children unaided and do not delegate any of the responsibilities to other members of the family. Mothers believed that nobody could take care of their children except for themselves, and therefore they seldom set aside any time for themselves and their own needs. All of the mothers remarked that they do not want to spend time on their own self-care due to the stress they feel about their children: "I don't get any pleasure from life because he is always on my mind." One of the other mothers stated:

"I see my health as being totally dependent upon his health, I only wish him to be well and able to stand on his own two feet and take care of himself. For this reason, I am devoted to him".

When mothers devoted themselves totally to their children, they ended up neglecting themselves. In our study, the majority of participants stated that they have no plan for their own life, and they solely think about their children. One of the mothers stated:

My life is very routinely with daily chores. I am always at home, no plans, no entertainment, my

days are repetitive ... I don't do anything for my own well-being ... when he is at school, I have to do housework, cleaning, shopping, cooking, etc ... I have to carry out all my responsibilities. When he comes back home I devote myself to him. Thus I have no time for caring for myself ... that is why I neglect myself ... I have not had a routine check up or cancer screening for over six years. I feel unwell and no one is guiding me.

Therefore, high degree of devotion in the long time, without external support inevitably leads to the aforementioned stress, self-neglect and feelings of helplessness. Therefore, the comprehensive understanding from our study is that Iranian mothers who are living with children with learning disabilities have to "*grin and bear/put-up and shut-up*".

## Discussion

The results of our study show that a child with a learning disability in a family impacts upon the mother's life, the relationships between different members of the family, and all the functions of the family. The affected features may be classified in social, physical and psycho-emotional aspects. The participants in this study described living with a child with a learning disability in a manner that has not been reported previously; that the experience was both positive and negative, fluctuating back and forth between the two polarities. In this study two major themes of living with a disabled child have been identified; *being the centre of stress circles* (being surrounded by stressful circumstances) and *being in the midst of life and death* (fluctuating between feeling alive and full of hope and being utterly drained and lifeless). In our study, one of the sources of support was spiritual belief. Mothers relied on their religious beliefs to cope with the situation. Some believed that the child is a blessing and a "godsend" and they should accept god's will. They added that they accept their child and they should be patient and they will be rewarded in another world (life after death), and this was the most important source of comfort for them, and helpful in creating a positive perception. For these mothers, a belief in God and the world after death helped them to accept anything as God's will. Therefore, they perceived their disabled children as a part of themselves. Their beliefs assisted them to be calm and relaxed. Stainton and Besser (1998) identified nine positive impacts of having a child with intellectual disability in the family as reported by parents. One of these was a source of "increased spirituality". In our culture, religious beliefs facilitate the process of child's acceptance and also living with a disabled child

would increase spirituality. In contrast, in other studies of family experiences, there is no reference to spiritual support and most emphasis is placed upon the social and family support (Skok, Harvey & Reddihough, 2006; Hockenberry & Winkelstein, 2005). However, other studies (Ostermann, Bussing & Matthiessen, 2004; Laubmeier, Zakowski & Bair, 2004) have indicated that spirituality can diminish depression, anxiety, and the sense of helplessness and can promote better mental health. In this study, however, spiritual support was accompanied by others sources of support such as; husband, relatives, friends, health worker and staff of school, it led to a sense of hope. In this respect, mothers of children with disabilities who were in the midst of life or on the positive polarity experienced a lower level of stress than those who did not.

According to the Family System Theory, any disorder in one of the sub-units of the family affects all other units in the system (Whaley & Wong, 2003). It is obvious that the internal and external systems of family could play an important role in the promotion of family's health. Relatives, friends and professionals reacted in various ways, both positively and negatively, to the child's disability (Luoma, Koivisto & Tamminen, 2005; Hassall, Rose & McDonald, 2006; Hastings, Daley, Burns & Beck, 2006; Eisenhower, Baker & Blacher, 2005). Encouragement may provide positive reinforcement and affect well-being and health. It has been reported that social support was found to have a role in mediating the impact of stress on these mothers (Skok et al., 2006). In our study, the majority of participants have to spend most of their time, physical and psychological energy, and endurance in taking care of and provide training for their child to learn basic daily life skills. Consequently they have experienced a great deal of stress in their lives; managing the activities of daily living of a disabled child was challenging as they did not perceive and receive any support from internal and external family system.

In this study, although mothers have religious faith and feel spiritually supported, majority of them still experience anxiety about the uncertain future of their disabled child, chronic sorrow and a sense of hopelessness. Despite the fact that they could accept their children, as the sense of spirituality was not accompanied with other sources of support, they were unable to successfully solve or manage all the problems that arose. This led to a feeling that they were trapped in a vicious circle of stress or they referred to midst of death or on the negative polarity. In addition, according to participants, husbands, relatives and friends were not able to meet their needs satisfactorily. Within the Iranian society, the

role of fathers is primarily defined in such a way that it is often limited to financial responsibility. Most of non-governmental services for children's health and educational needs are expensive, so the fathers have to work hard. Therefore, nurses could also provide a source of support; such as consultation, education, coordination with rehabilitation teams and form support groups for mothers with similar situations and provide guidance for them. This could lead to a more effective spiritual support and promote coping strategies. When nurses informed mothers of the available health care systems, the immediate worries regarding the child's needs included school placement and their state of health, whereas mothers' long-term concerns were mainly the child's ability to care for themselves and issues such as getting married, having an occupation and becoming independent, and the child's degree of self control. Effective social services and provisions could provide more tranquillity and respite for mothers. However, in our study mothers stated that those supportive systems were *not effective for them*. In fact, they were "ground down with pressure" and felt that they were walking in the dark, which resulted in negative feelings, unremitting stress, and burn out. One respondent said: "my son is 9 years old, but I feel that I have suffered for 90 years" and some of them described their situation as "not being able to run away from it, not able to leave it", and they refer to this as a negative experience. Alternatively, although mothers' experiences were both positive and negative, fluctuating back and forth between the two polarities they were more immersed in negative feelings "death" than positive feelings "life", and moving from "negative" to "positive" was very slow. As the sources of social support were limited and lacking adequate coordination, mothers were in the centre of a vicious circle of stress.

All respondents were lacking knowledge as to how to care for the child and how to make use of coping strategies. In addition, they do not have enough knowledge for creating a positive caring relationship between family and child (Hassall et al., 2006; McCarthy & Cuskelly, 2005). Hastings et al., 2006 reported that parental cognitions is influencing parental stress levels. So health care providers could increase parental cognitions and decrease their stress levels. Studies highlight how health promotion could improve quality of life in chronic situations (Wang, 2006; Tae, 2006). Whaley and Wong (2003) and Hockenberry and Winkelstein (2005) reported that supportive aids are one of the important factors that encourage families to cope with stress. Lack of these aids affects families' problems adversely. The findings of this phenomenological study can be used to

raise awareness amongst health care providers about what it is like to live with a disabled child, to promote insight and empathy, and to suggest strategies for coaching. Nurses within rehabilitation team can play an important role in helping the mothers to deal with these difficulties (Skotko & Bedia, 2005). They should have the responsibility of giving support and provide services to the children and their mothers (Sisk, 2000). Therefore, nurses would be able to reinforce the positive experiences of the caregiver they are supporting when they express a philosophy of life, which helps them to improve their well-being (Paterson, 2001). Many of the study's participants indicated they had developed a philosophical way of thinking about their disabled children that helped them cope with troublesome days. Nurses can support such positive attitudes. Nurses have to work within the multi-professional rehabilitation team and there are challenges for effective team working, families, governmental and non-governmental organizations, and society as a whole (Long, Kneafsey & Ryan, 2003).

### Conclusion

Nurses and other caregivers should become more aware of how living with a child with learning disability can be experienced by mothers like the constant swing of an emotional pendulum. Mothers did not identify having a child with a learning disability as an essentially positive or negative experience. This knowledge can provide a heuristic to help nurses and other caregivers to guide mothers in adjusting to having a child with a learning disability. The mothers highlighted areas that professional health providers must consider in order to be able to improve their social, physical, and psycho-emotional quality of life. The attention paid to "managing self care and child needs", "support" and "spirituality" by mothers showed that they were not progressing along the road toward the ultimate goal of being an effective mother. However, their enhanced awareness and received support provided by the rehabilitation team, ensures progress in this field. Professionals, therefore, have a very important role to play in this cultural context.

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