

# Bitter experiences of elderly parents of children with intellectual disabilities: A phenomenological study

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## ABSTRACT

**Background:** It is predicted that over the next 30 years, there will be a significant increase in the number of elderly parents who care for their children with intellectual disability. This paper is part of a larger qualitative study which investigated the unpleasant experiences of these parents.

**Materials and Methods:** A phenomenological approach was adopted and data were collected through unstructured in-depth interviews with elderly parents of children with intellectual disability. The data were analyzed using Colaizzi's seven-step method.

**Results:** "Bitterness" is one of the four emergent themes extracted in this study which has five theme clusters: inappropriate behavior toward the child in the society, the society's failure to support the child with intellectual disability, sorrows experienced by parents, the child's problems, and barriers in the care of the child with intellectual disability. One significant barrier in the last theme cluster is limitations due to aging.

**Conclusions:** The findings of this study suggest that the elderly parents of children with intellectual disability experience many sorrows and unpleasant feelings, but they mostly consider the social factors as the cause of problems and not the presence of the child. The results also indicate that older parents cannot look after the child as before in their old age; so, future well-designed studies are required for identification of the process of supporting them.

**Key words:** Child, children with intellectual disabilities, elderly parents, intellectual disability, Iran, parents, phenomenology, qualitative research

## INTRODUCTION

When we speak of "the elderly," usually the image of persons who need attention and support is got in the mind.<sup>[1]</sup> Although in many cases, the elderly,

indeed, do need various kinds of support, in this study, we speak of the elderly who not only pass through their aging process requiring support for themselves, but, at the same time, must be the support and service provider to another person who is their child with intellectual disability.

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Few studies have been conducted on families in which persons with intellectual disabilities are supported by elderly parents. These studies have mostly been carried out by quantitative methods and focus on young parents of children with intellectual disability. These studies show a wide spectrum of differences in terms of results.

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Some studies suggest that the existence of children with intellectual disability in families causes serious adverse effects (e.g., increased stress and anxiety) for the parents.<sup>[2,3]</sup>

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However, other studies do not confirm the above results and refer to the positive effects of a child with intellectual disability for the family. An example in this case is a study by Greer *et al.* in Ireland. According to its results, most of the mothers experienced that their child is a source of happiness or fulfillment, a source of strength that increases the closeness of the family, and a source of personal growth and maturity for the parents.<sup>[4]</sup>

Conversely, some studies suggest that the existence of children with intellectual disabilities in families has serious adverse effects. Among these, the study by Barbosa *et al.* can be quoted.<sup>[5]</sup> Emotions such as anger, rejection, and lack of affection have been reported by the mothers reporting in this study. However, this might have been replaced at a later point in time by love. In another study conducted in Pretoria by Pilusa, analysis of data collected by semi-structured interviews indicated that parents have had experiences such as nervous breakdown and shock, despair, grief, sadness, uncertainty, embarrassment, fear, and denial.<sup>[6]</sup>

As it is expected that over the next 30 years, there will be a sharp increase in the number of parents older than 80 years who take care of their children with intellectual disability,<sup>[7]</sup> different aspects of the life in these elderly people should be examined in detail. Caring for an intellectually challenged child is a subjective, complex, and multi-dimensional phenomenon that depends on personal experiences and perceptions as well as on the socio-cultural context. Since there is not much information about it, and the findings of the available studies show great differences, a qualitative approach and phenomenological method was used in this research.

## MATERIALS AND METHODS

This research was part of a qualitative study with a descriptive phenomenology approach in which data were analyzed using Colaizzi's method. As part of the main study (which was a thesis for MPH degree in Gerontology), this paper describes the unpleasant and bitter experiences of the elderly parents of children with intellectual disability.

### Data collection and analysis

This study was approved by the Ethics Committee of University of Social Welfare and Rehabilitation Sciences, and conducted from December 2011 to November 2012.

At the beginning of the study, potential participants received and signed the informed consent form containing information on the process of the study. Other ethical principles such as confidentiality and anonymity of research participants were applied too. Inclusion criteria were willingness to participate,

age 60 years and over, and having a child with intellectual disability. The exclusion criterion was unwillingness to participate in the research. This means that the study was carried out with volunteers. The number of participants was not known in advance, and the interviews were continued until data saturation was achieved. Data collection was carried out through unstructured, in-depth interviews.

Ten elderly parents whose children were participating in rehabilitation and training measures at the Comprehensive Rehabilitation Center of Amal Charity participated in this study. The center is located in the north of Tehran and offers various services such as job training, medical facilities, rehabilitation, and care for children with intellectual disability and their families. They are generally referred to the center from different areas of Tehran and its suburbs which have various socioeconomic situations.

Interviewees included five women and five men, aged 60–72 years. Two men and two women were spouses. They were selected by purposeful sampling. Each participant could choose the date and time of interview and they all agreed to attend the interview at the center as well. Before the first interview with these volunteers, a pilot interview was conducted. All interviews were recorded and transcribed literally before they were analyzed. For analysis, the Colaizzi seven-step approach was applied.<sup>[8,9]</sup>

### Rigor

In this research, the following approach was used to establish trustworthiness:

- “Bracketing,” which is an elementary step in a Colaizzi's phenomenological method<sup>[9]</sup>
- Prolonged engagement with data, which was continued throughout the research process
- Use of iterative questioning in the interviews
- Expert check: Holding weekly meetings with supervisors to monitor all stages of the research
- Presenting the results of the fourth and fifth steps of Colaizzi's method (clustering and rich description) to the expert panel
- Receiving the final comments of the participants (elderly parents) about a summary of the interviews as well as the results of the research (member check). They recognized that the results represent the experiences they have because of having a child with intellectual disability.

### Ethical considerations

As mentioned above, this study, which was part of a thesis for MPH degree in Gerontology, was started after it was approved by the University of Social welfare and Rehabilitation Sciences (Registration no.: 950-140).

## RESULTS

The following four themes emerged from the data analysis: “bitterness,” “emotional attachment,” “spirituality,” and “support satisfaction.” In this paper, we mainly describe the theme of “bitterness.”

### Bitterness

It includes the following five theme clusters: experience of inappropriate behavior toward the child in the society, experience of the society’s failure to support the child with intellectual disability, sorrows experienced by parents, experience of child’s problems, and barriers experienced in the care of the child with intellectual disability.

#### *Experience of inappropriate behavior toward the child with intellectual disability in the society*

Based on the experiences of the study participants, parents often have uncomfortable and even humiliating experiences because of the presence of the child in the society. One of the main reasons why parents get upset in these cases is other people staring at the child. Regarding the experience of people giving unusual looks at the person during childhood, a mother explains in this way, “*when someone stared at my child, I got upset, and I grieved over the child.*”

Other experiences suggest that there is discrimination against their children. This discrimination was evident in some cases, and had an insulting aspect. For example, a mother said that some people do not put plate and fruit in front of her child: “*They put fruit in front of everyone, but I saw that they didn’t put it in front of him. I picked up my fruit and put it in front him, so that they would understand how much he means to me and never repeat this.*”

Parents expressed their experiences about the reduction of social relationships. Most parents have reduced their contacts with families who do not have a good relationship with the child with disability. However, most parents have stated that the child is interested in social communication. An elderly father of a child with intellectual disability said, “*I go to the place where they primarily accept the child, and if I go somewhere and they reject him, I would certainly terminate my relationship.*”

#### *Experience of the society’s failure to support the child with intellectual disability*

Some of the experiences by these elderly parents were related to the society’s negligence to a child with disability, which had different aspects:

Almost all parents stated that the society does not have sufficient facilities and resources for effective participation

of the person with intellectual disability in the society. For example, there is no possibility for their activities in the public sports facilities, and the parents believed that the support of the society is not enough for them. A father said, “*We took him to a fitness club on his request, but I saw that they do not have a special coach for these children. After a few sessions, I no longer took him to the club.*”

#### *Sorrows experienced by the parents of persons with intellectual disability*

Parents of persons with intellectual disability had experienced many sorrows during the care of their children. The majority of them compared their child with age-matched healthy individuals; and the regret of this comparison was evident in their talks and was mentioned implicitly in some other cases. A father stated this comparison as follows: “*As far as I know, he should have gone to college. Children of the same age have gone to university, and he should have been married by now.*”

One reason for the discomfort experienced by parents was that their children are aware of their disability status and compare themselves with healthy individuals. An elderly mother said, “*I tell her to dance, but she does not dance, she is embarrassed. She tells me, ‘How can I dance with these feet?’ I tell her, ‘no problem, go, there are children who are worse than you.’ She does not want to dance, but likes parties. I take her everywhere.*”

Elderly parents have had to bear the burden of ordinary life and follow different kinds of medical care, and comply with the educational and rehabilitation needs of their children. One mother said, “*We took him to school and brought him from school every day; he had so much homework. I worked until noon at home. When he came home and I wanted to work with him, it was night and I was not much able to work with him.*”

While the parents become older and more fragile, they do not get effective support in the society. The inability of the children with intellectual disability to defend themselves and their simultaneous need for care creates a condition in which the parents become concerned about the future of their children after they pass away. A retired mother stated this concern in simple words, “*I think all about the future and his situation after me (severe crying).*”

Another mother said, “*However, I serve him as long as I can. But because I know it will be too hard for him if I’m not alive, my greatest wish is to die together (tears).*”

In addition, there had been strong primary negative feelings in some of the parents which were relatively controlled

later. A mother describes the emotions she had in the first years after the birth of the child: *"I was anxious, agitated, such a person who is stuck in a swamp. I was sinking. My life was overwhelmed by sufferings and problems."* This mother who takes part in the workshops for families of children with disability also explains how her attitude has been changed: *"I changed my view points later. Not only it influenced on me, but also on my family, I don't look at the subject as before."*

### *Experience of the child's problems*

Although the participants' experiences indicate that parents are pleased with their children and have no serious problem with them, it cannot be said that the presence of children with intellectual disabilities has not caused any inconvenience to them. For example, some of them said that the child speaks up or speaks improperly so that he/she upsets people close to him/her: *"Sometimes he talks a little aloud. I get upset. I say, 'your brothers are asleep ... they may wake up ... they have small children.'"*

Parents, especially mothers, had encountered physical problems and diseases of the child. A mother explained the problem in this way: *"I took my kid to the physician almost every day, because he has low resistance to infections. This is why he regularly gets sick ... it causes an economic burden for the family."* A mother explained about the need of marriage in their children: *"Like other people, they should get married, they should have a home, and enjoy their life."*

### *Barriers experienced in the care of the child with intellectual disability*

Elderly parents of children with intellectual disability also faced barriers in child care. Financial problems are one of the barriers mentioned in some interviews. For example, one mother said that her child loves music, but she cannot enroll the child in these courses: *"My income is not enough to enroll him in a private class so that he can learn music ... but he is interested in music, he likes it a lot."*

In some cases, the lack of coordination between parents has been expressed in performing care, but most elderly parents showed satisfaction and pleasure with the services provided by them and their spouses. They had implicitly referred to the uncertainty of child care by other family members after their death, although they said that they expected nothing from other children in this regard. An elderly mother explained it in this way: *"His sister goes to work in the morning and comes back in the evening ... they are not responsible for him. We can give no responsibility to them in this regard. Neither I nor his father expect anything from them."*

In some interviews, aging and its effects have been described as a barrier to continue to provide appropriate care. An elderly mother described the effects of aging in this way: *"Those days, I was younger, we lived in a basement of an old house with two kids, but I was not afraid of work pressure. Nowadays, although we live in a comfortable apartment, I cannot work as before, because of old age."* Another mother stated, *"When I was younger I had the ability to look after him (the child), but now I cannot even do the dishes."*

In this study, three other emergent themes were extracted that are briefly mentioned below.

### **Emotional attachment**

Participants in this study had an emotional attachment to the child. This attachment was expressed more in the single mothers who lived with their children. They believed that their child was a factor that prevented them from being alone. In this study, there was no concept indicating that the parents had negative feelings toward their child or they considered him/her as the cause for their problems. A single mother who lives with her only daughter said, *"If she was not with me, I would become alone and my condition would become worse."*

### **Support satisfaction**

Parents were satisfied with the informal support provided mostly by their family, friends, and acquaintances. It included not only material but also emotional support. One of the male retired seniors explained about the support received from his colleagues: *"My colleagues were very good and I loved them very much. They knew my problems and were very careful to keep me from thinking too much about the problems."*

### **Spirituality**

Although the parents have had difficulties with raising up a child with disability, they mostly have a spiritual attitude toward the child now and consider him/her as a gift of God. A father stated, *"God gifted me this child and I pay attention to him more than my other children."* More details about this emergent theme have been presented in another paper.<sup>[10]</sup>

In general, it can be said that the elderly parents who participated in this study have had many bitter experiences in their lives. One of the most unpleasant experiences was inappropriate behavior with disabled children in the society. They believe that the society has not effectively provided sufficient conditions and facilities for the presence of a disabled child in the society. They feel burdened with all child care responsibilities and have experienced many sorrows too. The participants in this study had a strong concern toward

the future of their children after the death of parents and they believed they could not look after the child as before due to aging. They believed that financial problems are significant barriers of caring their disabled children. Inability of children to lead a marital life is another major problem experienced by parents. However, it cannot be said that all the experiences by these elderly parents are unpleasant. For example, spirituality and emotional attachment to the child are the other emergent themes in this study.

## DISCUSSION

In this study aimed at describing the experiences of elderly parents of children with intellectual disabilities, data from 10 unstructured interviews with the parents were analyzed using a phenomenological approach and Colaizzi's method.

The findings showed that one significant emergent theme is the experiences of "bitterness" by parents, the most obvious of which is related to the presence of their children among other individuals in the society.

The findings also indicate that the parents have concerns about inadequate supportive resources in the society for them. On the other hand, while the child cannot live independently, the older parents feel that they cannot look after the child as before because of aging and physical weakness. This situation results in severe concern about the child's future, particularly after the death of parents. So, it is suggested to study the process of supporting them by other methods such as grounded theory in further studies.

According to the findings, it can be understood that although the parents are faced with problems such as financial difficulties and lack of supportive resources in child care, they mostly consider environmental factors such as lack of social support and not the presence of the child as the cause of their problems. In other words, the parents do not attribute the problems to their children.

The results suggest that older parents have a spiritual attitude toward having a child with disability. On the other hand, the presence of a child with disability may help the parents to overcome loneliness in the old age. So, their emotional attachment to the child can become stronger, especially seen among single mothers. Although "spirituality" and "emotional attachment" which have been expressed by parents can assist them to cope with problems and unpleasant feelings, the process needs to be investigated by further studies.

The results of this study differ from the findings of the studies that are mostly quantitative and have introduced the children with disability as the cause of problems such as loss of social relations.<sup>[11]</sup> Data from the experiences of participants in this study suggest that parents have little social communication, but there is no indication that the presence of children with disability has reduced these communications. Rather, parents have exclusively reduced their relations with families that do not have appropriate behavior with their children.

In line with the results obtained, the study of Barbosa *et al.* can be also mentioned.<sup>[5]</sup> Primary emotions such as anger and rejection of the child and lack of affection have not been reported in the present study. Concerns about the child's future after the death of the child's parents, which is a clear theme in the present study, has not been reported in the study of Barbosa. Cultural differences and spiritual perspectives may be the reason for the difference in results.

The themes related to the experiences of bitterness in this study are similar to the negative emotions described in the study of Pilusa,<sup>[6]</sup> which include nervous breakdown, despair, grief, sadness, uncertainty, shame, bitterness, lack of faith, suffering, fear, and denial. The same negative emotions have been also reported by Mohammadkhan-Kermanshahi *et al.*, who conducted a qualitative study on the experiences of mothers of children with intellectual disability.<sup>[12]</sup> In the present study, neither denial nor disappointment has been reported; other negative feelings in the studies are very similar to each other.

Descriptions by elderly parents in the present study suggest that the care of the child does not present severe stress and most of the problems are caused by the lack of adequate support, rather than a child with intellectual disability. A study conducted by Minnes and Woodford<sup>[13]</sup> reports that the increased age of the parent caring for child with intellectual disability causes no additional stress for the elder. In both the studies, there are similar concerns about the child's future and participants are worried about the future of their children.

In another study, Kearney and Griffin reported that parents of children with developmental disability have had hope, love, strength, and joy against their sorrows.<sup>[14]</sup> Kausar *et al.* reported that spiritual beliefs enable parents to define and interpret the presence of the child with disability in a positive way.<sup>[15]</sup> Spiritual attitudes toward having a child with disability can be noted in the other studies such as Pilusa<sup>[6]</sup> and Haworth *et al.*<sup>[16]</sup> too, which are in line with the results of the present study.

Altogether, it can be said that a significant number of bitter experiences and feelings are common in the above studies, but the feeling of acute concern about the child's future after the death of parents is more tangible in the present study compared to the others. Further research is required in order to find the reason of these differences.

## CONCLUSION

The results of the present study indicate that older parents of children with intellectual disability experience many unpleasant feelings which are greatly attributed to social factors, but the parents do not consider the child as the cause of problems and even have an emotional attachment to him/her. The findings also indicate that the older parents cannot look after the child as before because of increased age and they also have great concerns about the future of the child after the death of parents. This study does not reveal how can parents be assisted to experience less difficulties; so, it is suggested to investigate the process of supporting them, by other methods such as grounded theory in future studies.

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## Conflicts of interest

There are no conflicts of interest.

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