

Perceived Experiences of Life Problems for Parents with a Down Syndrome Child

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Abstract

Aims: Down syndrome (DS), as the most common cause of mental retardation causes many health problems for families. This study aimed to investigate the experiences of life problems for parents with a DS child.

Participants & Methods: This qualitative research was conducted using the conventional content analysis method on 21 Iranian parents with a DS child of over one year of age. Data were collected using online asynchronous interviews in 2017. Snowball sampling was continued until the data saturation was reached. Data collection and analysis were conducted simultaneously by qualitative content analysis.

Findings: Participants included 21 parents of children with DS in the age range of 28-49 years old. The analysis of qualitative data led to the extraction of three main themes, including "continuation of a difficult life", "inappropriate atmosphere of the community for acceptance of a child with DS", and "perceived future concerns".

Conclusion: The findings showed that parents of children with DS had major common concerns about taking care of their children. It is necessary for health policymaker and healthcare providers to pay more attention to the implementation of medical care and education programs for children with DS. Also, informing the community about DS helps to raise awareness and appropriate social interactions among the families and community members.

Keywords

Down syndrome [<https://www.ncbi.nlm.nih.gov/mesh/68004314>];

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Introduction

Down syndrome (DS) or trisomy 21, as a chromosomal disorder with a frequency of one per 800 live births, is known as the most common cause of mental retardation [1]. Children with DS are often faced with problems such as congenital heart disease, respiratory illness, auditory and visual impairments, hypothyroidism, metabolic and musculoskeletal disorders, and functional impairments [2]. Due to their cognitive and motor skill deficits, most of these children pass through the growth and developmental stages with a delay of about twice the normal time [3]. The birth of a child with DS affects all the family members. In addition, taking care of such children at home needs a lot of time and imposes high costs on the family [4]. One parent, especially the mother, must spend more time and energy to take care of the child, which often causes her to lose her job. Considering this situation and the high costs for taking care of a child with DS, the financial security of such families is at high risk. Psychologically, parents experience emotions such as fear, depression, anxiety, and guilt. They may also consistently compare their child with normal children and blame themselves. Moreover, inappropriate interactions with others, the presence of other children in the family, and problems in marital relationships can decrease the quality of life in these families [5].

Studies on the experiences of families with DS children indicated that despite some few shared experiences between the parents of a child, different families had unique and different experiences. Kortchmar *et al.* studied the experiences of women with DS children in Brazil and found most participants were concerned because they did not know who would take care of their children in the future, they did not have enough time to take care of their children, and their personal aspirations and desires were postponed [6]. Hanson stated that the most important challenges of families with DS children were coping with medical problems, harassment, and exclusion of their children by others, and disappointment with the child's ability to reach the strengths of adults. The parents of children with DS were disappointed due to the lack of support from the related formal and informal centers and the poor quality of the rendered services, especially when children reached puberty. However, some families reported positive results including the family's pleasure from the birth of a child and the creation of new parenting or sibling roles [7]. Also, Majd *et al.* reported major problems with DS families are classified into seven groups including physical, mental, behavioral, social, educational, maintenance, support, and communication problems [8].

Having a child with DS in the family reduced the parents' quality of life due to increased problems

and disruptions in family functioning [9]. Increasing adaptability, satisfaction, and well-being both parents and children require better communication between parents, community and health system by identifying their needs initially [10]. A qualitative approach helps to understand the problems and concerns of families with DS child and the way through which they define their conditions. In fact, a goal of qualitative research in the field of health is providing a multi-dimensional perception of the individual's experiences in a situation. In qualitative studies, the individuals' emotions and perceptions are described, which can be the basis for changing the health-related policies of the society. This approach is particularly useful with regard to the untouched areas, which have not been studied previously and contain major gaps in their literature [11]. Despite the importance of this subject, very few native studies dealt with it using quantitative approaches [9, 12] and we are still faced with a great gap about perceptions and experiences of family members especially parents of children with DS.

The present study aimed to explain the parents' experiences of living with a DS child.

Participants and Methods

This qualitative research with conventional content analysis was carried out to explain the parents' problems and experiences in living with a child with DS. The participants included 21 Iranian parents with a DS child over one year of age. Based on the willingness to participate, one parent or both father and mother entered the study. The data were collected in about 11 months using online asynchronous interviews in 2017. The online asynchronous interview is an in-depth interview, which is usually conducted via e-mail but differs from the email surveys. This interview has a semi-structured nature and involves the exchange of various emails between the interviewers and interviewees over a long period of time. This type of interview can be useful for those who prefer to interview online instead of face-to-face interviews, as well as those who are not easily accessible to the researcher or geographically far apart [13]. Participants with deep experiences were initially selected by purposive sampling method. Then, the snowball sampling method was applied until complete data saturation was achieved. These parents knew each other from the virtual networks and were willing to participate in the study. However, despite their first-hand and rich information, they could not attend face-to-face interviews. So, they were selected to attend the online asynchronous interviews. In this regard, the first participant, who had a blog about the daily routines of her DS child, was asked to introduce other families with DS children. After the initial introduction, informed consent forms, detailed

information of the study, and participants' required information form were sent to the parents. After announcing their consent, the participants were asked to answer the research questions, attached with an instruction form, within two weeks by email. In the case that they did not respond in two weeks, reminder emails were sent to them at intervals. The participants were initially informed that they may receive several emails to collect detailed and clear information. In this study, the minimum number of email exchanges between researchers and participants was three times, whereas, the maximum number was five times. Each interview lasted from one to three weeks.

The main question of the interview provided by the authors was: "What were the problems you experienced for taking care of your DS child?" More detailed questions were asked with regard to the parents' first responses in the subsequent emails. Some of follow up questions include: "What problems do you have to take care of your child's physical and mental health?", "What problems did you experience about your child's attendance in the community?", "Given the specific needs for children with DS, does a community institution support them?" "What problems do you think will happen to your child in the future?". The interview questions were piloted in terms of its language, relevance, and difficulty of words by an expert panel and some parents who were outside of the study. Finally, the necessary changes were made.

In online asynchronous interviews, if a question is not clear to the interviewee, more detailed and elaborated questions will be sent to them. In order to ensure the participants' privacy and data confidentiality, they could use a fake email address with nicknames.

In qualitative research, data analysis is conducted simultaneously with the data collection. Therefore, after receiving the first response, the interview text was read and broken into the smallest meaning units. In this study, the conventional content analysis method was used for data analysis. Content analysis, widely applied in qualitative research, is a method of analyzing written communication messages that allows the researchers to test the theoretical issues in order to enhance data comprehension [14]. In this method, hidden codes and themes are identified and derived from the participants' comments using a systematic classification process [15]. So, after the end of each interview, the contents were immediately transcribed and reviewed several times to obtain a general insight. Then identified meaning units were summarized and labeled with understandable concepts as initial codes. The various codes were reviewed frequently and the same codes merged. Next sub-themes were classified based on the similarities and differences between the codes and finally, themes were extracted as well.

To ensure the accuracy and reliability of the qualitative data, four recommended criteria of credibility, dependability, transferability, and confirmability were used [16]. In the present study, the credibility of the collected data was obtained by the researchers' long-term engagement with the study subject and data, which required them to review the information continuously over a period of one year. In addition, the participants were provided with the initial codes to review and correct them in the case of any mismatches. The dependability of the collected information was confirmed by a comprehensive description of the research details, the complete record of the data collection stages including transcription, codification, and analysis. Also, the data were presented to two Ph.D. students who had experience in qualitative research and were not related to this study. Then, the similarity of their perceptions from the data was measured. Confirmability of the study was achieved through an audit trail which is described, as well as choosing proper interview technique and protecting informants' identity. Selecting parents from different categories of gender, age, occupation, educational level, and socioeconomic status was used to provide data transferability.

Findings

Participants in this study consisted of 14 women aged 28 to 49 years, and 7 men aged 30 to 47 years. The majority of participants (52.38%) had academic education. In terms of occupation, 11 individuals (52.38%) were housewives, 6 (28.57%) were employees, and 4 (19.05%) were self-employed. According to the findings, 13 participants (61.9%) had two children and the children with DS were the second child in most families (47.61%). Furthermore, 57% of children with DS were boys. The mother's age range at pregnancy was 24 to 42 years old. The analyses of interviews resulted in three main themes of "Continuing a difficult life", "Inappropriate atmosphere of the community for acceptance of a child with DS", and "Perceived future concerns" (Table 1).

1) Continuing a difficult life with a DS child

Life problems of parents with a DS child start from the baby's birth and continue throughout the baby's life. Each parent experiences a relatively wide range of problems in relation to the child, which leads to a difficult life. This theme included three sub-themes: "My child never gets well", "Life with a halo of negative emotions", and "Heavy burden of childcare costs."

1-1- My child never gets well

Children with DS are struggling with many diseases throughout their lives. They are often born with a variety of physical and mental disorders, which require special care and treatment. Problems such as congenital heart disease and hypothyroidism as well as digestive, kidney, speech, behavioral, motor,

and developmental problems were mentioned by parents.

"These children do not have one problem to be solved and then you feel comfortable. They are born with a thousand kinds of pain and diseases. My daughter's heart valves had a problem when she was born and we had to operate it. She also had hypothyroidism. Put all these things aside, as she is growing, she is developing new problems. So, we have to take her to different physicians. It seems that my baby never gets well" (Female participant, 37 years old).

"When you have a child with DS in your home, it means that you cannot have an easy life like the other people. A series of their general problems may get a little better, but they are not completely healthy. They constantly need a doctor, especially when they are younger". (Male participant, 40 years old)

Table 1) A summary of themes, subthemes, and codes derived from analysis of problems for parents with a DS Child

Themes/ Sub-themes	Codes
Continuing a difficult life	
My child never gets well	- Continuing physical disease during the life of children with DS - My kid needs a doctor constantly.
Life with a halo of negative emotions	- Feeling of sadness and stress from the birth of the child until now - Heartbreak due to the constant judgment of others - Feeling guilty and shocked due to having a child with DS during the past three years
Heavy burden of childcare costs	- High medical care costs include training and speech therapy. - Increasing care costs with the age.
Inappropriate atmosphere of the community for acceptance of a child with DS	
Inappropriate social interactions in dealing with a DS child	- Exaggerated compassion of community members when dealing with a DS child - Avoiding people from dealing with a DS child
Lack of adequate awareness in society	- lack of awareness of families about Down syndrome
Lack of adequate community infrastructure for supporting the family	- Lack of appropriate medical care centers for children with DS - Lack of educational centers for children with DS
Perceived future concerns	
Concerning about passing through the stages of growth and development	- Concerning about passing through of growth as a normal child - Thinking about the child's future in the absence of parents
The unknown future	- Worrying about not being independent in the future

1-2- Life with a halo of negative emotions

With the birth of a child with DS, parents experience a wide range of emotional feelings. Shock and disbelief caused by hearing the bad news from the physician or seeing the appearance of the baby,

discomfort, heartbreak, fear, anxiety, denial of reality, and feeling frustrated were among the subjects mentioned by participants. These feelings continue with some degrees of severity and simplicity during the lifetime with a DS child. Some other factors that jeopardize the psychological health of parents include hearing ironies from others, being judged inappropriately, feeling guilty and blaming oneself for having this child, feeling helpless to continue taking care of the child, and the pathetic feelings by the surrounding people.

A 35-year-old male participant said: "I did not believe my eyes when I saw my baby in the hospital, I felt thunderstruck for a moment because he was my first child. For my wife, it was more painful and distressing. All mothers wish giving birth to a healthy child after nine months of pregnancy with suffering and difficulty. However, since my son was born, we experienced more discomfort, anxiety, and stress instead of being happy".

"The family members did not dare to say anything to me, but they backbit me a lot; they said to each other; did you see what happened to her? Did you see how her son is? Furthermore, when they want to show their affection, they pet my son and say, Oh! Poor baby! I may control myself in front of others, but these things really spoil my spirit and break my heart." (Female participant, 28 years old).

"After three years from my baby's birth, my husband is still shocked, sometimes he blames me and sometimes he blames himself. He is more bad tempered and taciturn than the past. I feel our relationship is not as well as the past. I say to myself, what did I do that deserve this disaster? Sometimes, I get tired of everything and I do not want my child. Then, I sit alone and cry for hours." (Female participant, 29 years old).

1.3- Heavy burden of childcare costs

Many participants pointed out the high costs of treatment and care for children with DS. Particularly, families with only one working parent or women who were separated from their husbands felt much more difficult to live.

"I am an employee, but my wife left her job and stayed at home because of my child, I do not think she can work for a long time. Currently, all expenses such as medical, education, and speech therapy costs, as well as the costs of two other children are up to me. Considering the present expensive trend in the market, the situation is so hard for me. When my children grow up, I have to pay for kindergarten and school too. I'd love to do whatever I can for my children, but the costs of some of these classes are so high that are usually left in the mid-way." (Male participant, 47 years old)

"For a woman, it's even hard to afford the costs of a healthy child, put aside a child with problem; the costs get 10 times higher. As the kids grow up, their costs also increase because of their needs." (Female participant- 30 years old)

2) Inappropriate atmosphere of the community for acceptance of a child with DS

The main problem for parents of children with DS was related to the community: Inappropriate behavioral interactions of the community members, limited awareness and lack of adequate education in the society about DS, and finally, lack of adequate community infrastructure to support the parents of these children. These problems make society uncomfortable for the presence of such children. This theme includes three sub-themes of "Inappropriate social interactions in dealing with a DS child", "Lack of adequate awareness in society", and "Lack of adequate community infrastructure for supporting the family."

2-1- Inappropriate social interactions in dealing with a DS child

Some parents expressed dissatisfaction about the behavior of others with their children on the street, in shopping centers, or at recreation places. The individuals' avoidance to have contact with the DS child or expression of extreme-loving behaviors annoyed the parents. They expected others to treat their children as normal individuals.

A 43-year-old father said: *"In society, the people's reaction is either so bad or with much pity and compassion. They often gaze at us with amazement and chatter with each other. Another problem is that they ask about my child's problems at her presence, they do not look at these children as respectable citizens who can be useful for the society."*

The mother of an 8-year-old child described her previous experience: *"It's a little better now, but previously people treated children with disabilities very bad; so, parents preferred to take their children to the Welfare Organization. Sometimes that people gaze at us or change their path to avoid facing us; then, I wish I never came out of house."* (Female participant- 40 years old)

Another participant indicated: *"Some people are still considering DS children as dangerous disables and avoid facing them; when they see us in a park, they pull their children's hands to prevent them from contacting with our kid. Maybe I should not blame people so much, because I was a part of the same people before having a DS child."* (Female participant- 33 years old)

2-2- Lack of adequate awareness in society

Almost the majority of parents mentioned lack of awareness in the community about genetic diseases such as DS. This awareness was provided for neither the affected child's parents nor the other families.

One of the parents pointed to the difference between the viewpoints of people in Iranian and other societies considering the determinative role of awareness. He said: *"The Europeans, Americans, and people in the developed countries consider the issue of DS differently from the Iranians. We can determine this gap by having a simple search on the Internet. In almost all cases, you can see the family's happiness*

and the community's hope and attention. This is all because they are more aware than us. I read a sentence from a DS child on an awareness-raising advertising poster in the European community, which was more likely to be a religious proposition than a simple saying: God never makes mistakes". (Male participant- 36 years old)

"There are still many families that do not know much about children with DS unless they have a DS child in their family. There are no specific training programs. The TV may just show a program about these kids one day a year. Families with DS children do not know the extent to which these children can be trained, learn, and live a normal life. The atmosphere of our community is not ready for mentally or physically disabled people." (Female participant- 49 years old)

2-3- Lack of adequate community infrastructure for supporting the family

Although our participants were from different cities in Iran, most of them mentioned the lack of specialized centers for educating and taking care of children with DS. The Welfare Organization supports were often inadequate and non-specific.

One of participants said: *"There is no specialized center in our city; there are just some private centers of occupational therapy or speech therapy, which render services to children with autism, DS, and other mental disabilities. However, these children have different needs. Private clinics are just thinking about their income; sometimes, these kids experience worse psychological damages in these centers. The government needs to provide more services to families. Good occupational therapy and speech therapy centers are just located in Tehran and some big cities."* (Female participant- 40 years old)

"Practically, there is no special supportive organization. Some parents in some cities established some NGOs to provide supportive measures for their children; otherwise, there is no special training center for DS kids." (Male participant- 35 years old)

"If I want to go somewhere, I cannot leave my child with anyone. I even cannot take my child to a kindergarten because the kindergarten trainers do not know anything about these children. I even cannot find a nurse trained in this field. We are severely alone in the crowd." (Female participant- 28 years old)

3) Perceived future concerns

The participants had shared future concerns with regard to the current status of the community and the limited available resources. These concerns included two sub-themes of "Concerning about passing through the stages of growth and development" and "the unknown future."

3-1- Concerning about passing through the stages of growth and development

Parents of children with DS, especially mothers had concerns about their children's developmental stages. They liked their children to walk, talk, and eat like other children at a specific time. A 42-year-old mother talked about her concern: *"After each*

development stage, we are worried about the next stage. His teeth came in, we thanked God, then we were worried about his walking. Now, we are concerned about his speaking, the way to help him stop wearing diapers, and eating independently. These are the common development stages for all children, but it is like to a difficult match for us, we need to try more than other mothers to get it done."

3-2- The unknown future

One of the main concerns of participants was about their children's future; they had several common questions: What will happen to my child? Who will take care of him/her after my death? Can s/he have an independent life in society? These concerns proposed an unknown picture of the future for parents.

"I always think with myself, if I die, what will happen to my child? Who will take care of him? Who will help him? My friend, whose baby has a cerebral palsy, had a stroke and died. I think this happened because she was very sad about her baby. Now, her child is transferred to the Welfare Organization" (Female participant- 39 years old).

"I am worried because my child cannot be independent in the future. She may always need someone to support her and maybe even legally unable to access her property in the future." (Male participant- 45 years old)

"I am more concerned about the time that my child wants to enter the community alone, he may be abused. My nightmare is that when my child is alone, he may be abused by bad people. I do not know if he can take care of himself or not in the future." (Female participant- 37 years old)

Discussion

The results of this study on the problems of parents in living with a DS child summarized in three themes including the continuation of a difficult life, inappropriate atmosphere of the community for acceptance of a child with DS, and perceived future concerns. Living with a DS child probably includes a combination of different feelings and experiences, problems, disappointments, and satisfaction. So, it is important to have a detailed picture of it. Identification of different aspects in the family life of children with DS can satisfy their needs and provide the necessary support for their parents. Findings showed that these parents had a tough life and one of the effective factors in making these conditions more difficult was comorbidity in these children; some of their diseases will continue until the end of life. Similar to the results of this study, Bourke *et al.* reported the majority of children with DS in Australia had one or two physical health problems and almost all mothers reported at least one illness for their child during one year [17].

Children with DS are susceptible to a set of medical disorders and problems that are either congenital or provide the grounds for different infections and

recurrent diseases [18]. Therefore, the hospital personnel should provide the parents with a clear picture of the possible medical conditions that the child may have and prepare them to cope with these conditions. The negative emotions caused by the existence of a DS child, interactions with others, and financial problems associated with taking care of such children were among the mentioned problems. In many studies on children with different types of disabilities, parents experienced negative emotions such as shock, denial, depression, and anxiety [19, 20]. Of course, some studies have stated that parents had a positive feeling like love and hope about having a child with DS [21]. The important issue is the negative feelings may continue for a long time and cause chronic mental problems for parents. Supportive interventions, as well as appropriate training and communication practices, are among the existing therapeutic services that can help parents to admit the fact [22].

Consistent with our results participants in the study by Levis *et al.* believed that having a child with DS caused disastrous changes in their lives. They mentioned that financial problems increased stress and staying away from daily activities such as shopping and working made their lives difficult. Participants also indicated that finding appropriate care providers was difficult for their children [23]. Unfortunately, despite the well-known parents' need for better application of the health care system services, few studies were conducted on the health cost of DS children. A study in the United States showed that the health care costs for children with DS were 13 times higher than other children [24]. Geelhoed *et al.* also reported that the health care costs for children with DS were higher in the early years of life, which was mainly due to the cost of heart disease diagnostic tests and creation of an independent functional level [25]. Therefore, comprehensive research should be conducted over the cost of care for children with DS in all communities; so that, the governments can allocate the necessary budgets for the health programs. Given the widespread outbreak of DS in relation to other mental disabilities and with regard to the trainability of these children, the governmental sector should provide better financial support for these families.

The second theme of problems for parents with DS children was related to the barriers in the community. Some parents experienced rejection or inappropriate interactions from other community members which are similar to experiences of parents who participate in the study of Ahmad *et al.* with many feelings of stigma and social isolation [26]. Families of children with disability are faced with many various problems in societies with propagated inequality traditions. Daudji *et al.* showed that the value of people with disabilities defined by society could facilitate or prevent the parents' compatibility

with their children. Decrease of social interactions, social isolation of these children, and the parents' tendency to take them to care institutes instead of keeping them at home are directly related to mothers' feelings of shame and embarrassment as well as the families and societies' negative attitudes towards disability [27]. In addition, lack of awareness and education in the society about DS and lack of supportive institutions for DS children and their families made the atmosphere of community uncomfortable for the presence of such children. Similar to the findings of this study, lack of information and appropriate infrastructure in the community were reported in some studies conducted in other South Asian countries. For example, Ahmed *et al.* referred to the poor health care system and the lack of special services for people with disabilities in Pakistan. In the case of DS, they found no national or local guidelines on the diagnosis management of DS for care providers and no written information on the required conditions and cares of these children for parents. Although physicians know the disease condition, some of them did not use the scientific name of the disease and introduced the patient as "Mongol", that is a person with mongolism disease [28]. Identification and perception of the clinical features associated with DS is a key element in the determination and implementation of social and health cares that parents choose for their children. Parents can seek appropriate health care and support by being aware of the symptoms and consequences of this disease [29]. Awareness about genetic diseases among the community members can have a disease-prevention aspect and can be helpful in improving the individuals' attitudes toward dealing with disabled people.

The results showed that parents had two major concerns about their children; how will they pass through their developmental stages and the unknown future for their child. Similar to the results of the present study, Nunes *et al.* indicated that families of their study were mostly concerned about their children's future; concerns about the child's growth, independence, and support after parents. They argued that parents must prepare these children for an uncertain and unknown life and future; so, the children must be well prepared to be independent in the future [30]. Khan *et al.* also reported that the most frequent concerns about Kashmiri mothers were in relation to school, work, and marriage of children with DS in the future [31]. The common concern among all the families with disabled children was about the future. Parents of such children wanted their kids to be accepted as a normal person in the community. Therefore, they required the necessary facilities for education, job opportunities, and even marriage.

One of the limitations of this study is related to the data collection method of interview. Since parents

preferred non-face-to-face meetings, online asynchronous interviews were conducted, which can be a strong point of the study with regard to the application of a variety of methods in qualitative research. As another limitation of this study, the generalization of the results is difficult because the interviewed parents were involved in different socio-cultural contexts that could affect their experiences with DS. However, the findings included significant issues over the health executive programs that can help parents with disabled children, especially DS. The findings of this study can be helpful for health policymakers, managers of welfare organization and health staff to provide supportive medical and educational services according to the special needs of parents with DS child. They can also be beneficial for all community members to improve their social empathic relationships with such families.

It is suggested to perform further qualitative and quantitative studies with an extensive range of interviewing methods in different communities to better identify the needs and problems of families with Down syndrome.

Conclusion

Parents of children with DS were struggling with many problems related to their children, but they did not receive adequate emotional, financial, and health support from the community. The healthcare providers and community representatives should try to implement education programs for parents, provide easy access to care centers such as kindergarten and school, create secure jobs, and conduct ongoing medical programs to deal with these children's health problems. These measures can largely reduce the concerns and unpleasant experiences of parents and improve their quality of life and mental health. In addition, better communication of parents with the community and the health care providing system can prevent these children from isolation and retreat from social groups. The well-being of children with DS and their parents, as part of the community, should be considered as a fundamental human right in health planning.

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