

Coping strategies adopted by Iranian families of children with Down syndrome

A qualitative study

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Abstract

Down syndrome (DS) is the leading cause of intellectual disability. Previous quantitative studies have examined the effects of DS on families of children with DS. This study explored the coping strategies adopted by the families of children with DS. This was a qualitative content analysis study, in which the participants were selected using purposive sampling from the families of children with DS. Semi-structured interviews were performed and collected data were analyzed. A total of 20 family members (10 mothers, 6 fathers, 2 brothers, and 2 sisters) were interviewed. Six categories were extracted in this study, namely “searching for information,” “paying attention to children’s healthcare needs,” “concentration on spirituality,” “teaching socially appropriate behavioral skills,” “efforts to increase self-reliance in children,” and “development of family support circle.” The participating families were able to use positive adaptive mechanisms and cope well with the problems associated with having a child with DS. However, they still needed more support from healthcare providers and support organizations. Receiving more support from healthcare providers, such as nurses, can help them in better management of their children.

Abbreviations: DS = Down syndrome, SDH = social determinants of health.

Keywords: content analysis, coping strategies, Down syndrome, family experiences, Iran, nursing

1. Introduction

Down syndrome (DS) or trisomy 21, as the most common cause of mental, developmental, and learning disabilities, is caused by genetic disorders.^[1–4] The prevalence of DS is 1 in every 700 babies born in the world.^[5,6] Its estimated incidence is 1 per 1000 live births. Annually, 3000 to 5000 children across the world are born with DS.^[1,7,8] In Iran, the prevalence of DS is 1 per 814.^[9]

Individuals with DS encounter numerous health-related problems, such as delayed motor-neuron development, impaired

cognitive function, and impaired eye-hand coordination.^[10–12] Common health-related problems among children with DS, their effects on their quality of life,^[13] and related coping and adaptive strategies adopted by their families were studied.^[13–15] The results showed that in addition to reduced quality of life, they needed long-term care services.^[10]

Studies reported that stress is a significant factor affecting the function of families of children with intellectual disabilities.^[16,17] Although social support can play a crucial role in reducing parental stress,^[18,19] over 60% of families of children with intellectual disabilities and DS do not have adequate social support.^[20,21]

While suffering from several social problems, these families adopt specific strategies to meet their life needs so that they can effectively cope with the challenges associated with the birth of a child with a disability.^[22] A study reported that boosting hope can act as a supportive factor against psychological distress in these families.^[23]

Family is the core in caring for and raising children with mental and physical disabilities.^[13] Family-centered care is a key philosophy in pediatric nursing and nurses consider family members as full partners in the provision of healthcare to children.^[24,25]

Families can be key in altering risks to their members and they can easily fall prey to changing social policies and political systems, specifically potentially vulnerable families. The consequences for families with no support from healthcare providers are negative outcomes and less satisfaction with healthcare services.^[26] Furthermore, the assessment of parental problems and family functions provide useful information for nurses in adopting more effective family-based care interventions.^[27,28] To provide care to the family, understanding the nurse-family relationship is important.^[29] Constructing relationship is the base of nursing care practice.^[30,31] The health of families is integral to the health of its members, community, and society.^[32]

Editor: Massimo Tusconi.

The datasets generated during the current study are available from the corresponding author on a request.

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for profit sectors.

The authors declare that there is no conflict of interest.

Data sharing not applicable to this article as no datasets were generated or analyzed during the current study.

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How to cite this article: Gashmard R, Ahmadi F, Kermanshahi SM. Coping strategies adopted by Iranian families of children with Down syndrome: a qualitative study. *Medicine* 2020;99:28(e20753).

Received: 23 February 2020 / Received in final form: 15 May 2020 / Accepted: 19 May 2020

<http://dx.doi.org/10.1097/MD.00000000000020753>

There are scant studies into the effects of caring for children with DS on the quality of life of families and their coping strategies. It has been reported that the mothers of children with DS have lower environmental and mental health status. Moreover, negative attitudes of the community toward children with disabilities, economic issues, and inadequate support affect the quality of life in families.^[33] It has been revealed that children with DS have a whole range of social, behavioral, and physical problems and their parents suffer from psychological issues. Their mothers often receive little support from others and their siblings receive less support from their mothers.^[34] Therefore, there is a need for routine changes to meet family needs.^[35] Some families of children with DS may use resilience and adaptive skills.^[36] Other families may acquire adaptive skills through optimism about their future life, accepting their child's condition, making changes in their life routine,^[37] and using emotion-focused coping strategies to deal with stress.^[38]

Several studies have examined coping strategies in the families of children with DS and also the effects of behavioral and mental issues associated with this problem.^[13–15] Those studies mostly used quantitative designs and ignored the lived experiences of families. For instance, a quantitative study on Iranian families focused on parenting stress, emotional well-being, family functioning, and satisfaction with the caring role of families with children having developmental disabilities^[39]; whereas, parental experiences and coping strategies were not studied. On the other hand, there is not any study on coping strategies adopted by Iranian families of children with DS by cultural and social variations.

Information about the impact of children with developmental disabilities on Iranian parents would contribute to the development of more family-centered support services within Iran.^[40] It would also offer some insights into supporting Iranian immigrants in Western countries.^[27] Therefore, this qualitative study aimed to explore the coping strategies adopted by families of children with DS.

2. Methods

2.1. Design and participants

This study was approved by the Research Council and the Research Ethics Committee before the implementation of this study. A qualitative content analysis was performed to achieve an in-depth understanding of the study subject.

Participants consisted of the family members (father, mother, and siblings) of children with DS, registered in the welfare and rehabilitation centers of Bushehr City, Iran, and had medical records at these centers. Their contact information was extracted from their medical files. Today, many Iranian families use the services of rehabilitation centers and schools under the auspices of the Welfare Organization for their children with DS. However, there are few numbers of such support centers. Some of these centers provide services, such as speech therapy, occupational therapy, and painting, and teach some life skills, such as communication with others, greetings, handshakes, personal hygiene, reading, and writing, and basic concepts, such as money, primary colors, and recognition of the objects and their functions. There are also some semi-public vocational training centers under the supervision of the Welfare Organization for people aged over 14 years. In these centers, some painting, pottery, carpentry, sewing, and flowering skills, etc., tailored to the level of physical

and learning abilities of these children, are taught. In most supportive centers, the expenses are paid by both families and the government. The participants were selected through the purposive sampling method based on the following inclusion criteria: children with DS aged 18 years or younger, informed consent, and willingness and ability to express their opinions and experiences. A total of 23 families was invited to participate in the study, out of which 3 families refused to participate. What some parents said about siblings of children with DS led us to introduce some of them into the research.

2.2. Data collection

Data were collected through semi-structured interviews from July 2017 to August 2018. The interviews were conducted in private and comfortable rooms of the rehabilitation centers and the participants' own homes. The duration of the interviews varied between 40 and 55 minutes, depending on the participants' willingness and tolerance. Before the interviews, the researcher explained the research objective, ethical considerations, and interview schedule. Next, their informed consent to participate in the study and to record their interviews were obtained. The interview was conducted by a research team member with a Ph.D. candidate in nursing and where the interviewees were more comfortable. Since most families were referred to the rehabilitation centers for their children, they wanted to be interviewed there. Interviews were held in a separate room with the presence of only the interviewer and a participant. Those who did not feel comfortable in the center were interviewed at home if they wished. The researcher informed the families about the methodology and purpose of the study, which was the coping strategies adopted by families of children with DS. The researcher also briefed the participants about the voluntary nature of participation and the right to withdraw from the study at any time without any effect on the provision of care services. All participants were also assured that their personal information would remain confidential and entire interview files would be kept in a safe place with a lock in the workplace of the first author. The willing participants signed the informed consent form. Parental consent was also obtained.

During the interviews, the participants were asked about their experiences concerning how they deal with their children with DS and how they provided care to them. The interviews were started with a general question of "please describe 1 day of your daily life with your child." During the interviews, the researcher listened carefully to the interviewees' perspectives and encouraged them to give more explanations. Follow up and branching questions were "how did you adapt yourself to the presence of a child with DS in your family? What problems did you have concerning the caring and upbringing of your child? What are the effects of the presence of this child in your family? How have other family members adapted themselves to the presence of your child? Have you received any support and how?" Probing questions were also raised based on interviewees' responses to improve the depth of the interviews: "please explain more, what does that mean? How and why did that happen?"

2.3. Data analysis

Data analysis consisted of 4 stages: the selection of the unit of analysis (whole interviews); the determination of meaning units and description of them with a keyword or phrase (a code

associated with the text); condensing or shortening while the core concept is preserved; abstraction, description, and interpretation at a higher logical level and creation of categories.^[41]

The interviews were audio-recorded and transcribed verbatim after each interview and checked by the research team. A total number of 22 interviews were performed with 20 participants – 2 participants were interviewed twice. After conducting the first interview, some new questions were designed for data collection and asked from the next participant. Data collection was fulfilled simultaneously with data analysis until theoretical saturation was reached,^[42] that is when the categories and subcategories to answer the study questions were fully developed.^[28,42] The transcriptions were read several times to get the general sense. Next, meaning units were selected and condensed through the context-dependent methodology and specific descriptors. A list of codes was provided and the codes were semantically reviewed. The extracted codes were classified based on similarities and differences between them. The similar codes were condensed using an inductive method of reduction and defined at a higher level of abstraction and then the related categories and subcategories were determined and defined.^[41]

2.4. Rigor

The following measures were taken to improve the validity and reliability of the findings: data were analyzed by the first author and the analysis process was assessed and confirmed during intermittent meetings with the research team. The transcriptions were given to the participants for confirmation and modification. A brief description of the findings was presented to half of the participants for member checking, in which they were asked to confirm that their perspectives and experiences are reflected. For peer checking, the findings were reviewed by other researchers, who were familiar with qualitative research, and their comments were considered during the analysis. For credibility, the

maximum sampling variation in terms of social class and the severity of DS was considered. If required, more than 1 interview session was held with the participants.^[41]

2.5. Ethical considerations

This article aimed to determine coping strategies adopted by the Iranian families of children with DS. It was approved by the Ethical Committee of Tarbiat Modares University under the code IR.TMU.REC.1396.564. Before the study, the required permissions were obtained from the authorities. At the beginning of the interviews, the participants were given enough explanation about the purpose of the research, the method of interview, the confidentiality of information, and the right to participate or withdraw from the study. Then, the participants' informed written consent was obtained. The time and place of interviews were scheduled for participants' comfort.

3. Results

Six categories were developed: “searching for information,” “paying attention to children’s healthcare needs,” “concentration on spirituality,” “teaching socially appropriate behavioral skills,” “efforts to increase self-reliance in children,” and “development of family support circle.” Each category consisted of some subcategories. A total of 20 family members (10 mothers, 6 fathers, 2 brothers, and 2 sisters) were interviewed. The mean age of the parents was 46.31 years (SD=2.15 years), the mean age of the siblings was 18.75 years (SD=1.36 years), and the parents' education level ranged from a high school diploma to a bachelor's degree (Table 1). The data analysis led to 310 initial codes, which were classified into 6 categories. Each category consisted of 2 to 5 subcategories (Table 2). The categories and subcategories were described below using direct quotations from the participants.

Table 1
Demographic characterizes of the participants (n=20).

Participant	Family member role	Age (yr)	Level of education	Occupation	The child with Down syndrome	
					Gender	Age(year)
A	Mother	45	High school diploma	House spouse	Male	9
B	Mother	53	High school diploma	House spouse	Male	18
C	Mother	45	Bachelor's degree	Teacher	Female	14
D	Mother	33	High school diploma	House spouse	Male	4.5
E	Mother	36	High school diploma	House spouse	Female	5.5
F	Mother	53	High school diploma	House spouse	Male	14
G	Mother	51	High school diploma	House spouse	Male	17
H	Mother	46	Associate degree	House spouse	Male	4
I	Mother	43	High school diploma	House spouse	Female	5
J	Mother	53	Associate degree	House spouse	Male	10
K	Father	47	High school diploma	Fisherman	Female	13
L	Father	55	High school diploma	Retired	Male	17
M	Father	52	Bachelor's degree	Employee	Male	12
N	Father	35	High school diploma	Self-employed	Female	18
O	Father	38	Bachelor's degree	Self-employed	Male	10
P	Father	56	High school diploma	Unemployed	Female	12
Q	Brother	17	Student	–	Male	7
R	Brother	26	Bachelor's degree	Employee	Male	14
S	Sister	18	Student	–	Female	10
T	Sister	14	Student	–	Female	5

Table 2
Categories and subcategories developed in the study.

Categories	Subcategories
Searching for information	Trying to meet the needs of the child Learning about how to meet the needs
Paying attention to children's healthcare needs	The gradual development of information resources Treatment of physical problems and psychological disorders
Concentration on spirituality	Paying attention to prevention Belief in divine providence Prayers for peace Caring as worship
Teaching socially appropriate behavioral skills	teaching socially appropriate manners to children Exhibiting appropriate behaviors by family members Role-modeling for children and others
Efforts to increase self-reliance in children	Personal hygiene training The teaching of social interactions Assigning personal affairs to the child Giving the power of choice to the child
Development of the child- family support circle	Compensation for insufficient professional support by parents Increasing family involvement Pursuits of support services

3.1. Searching for information

The participants attempted to obtain the required information regarding how to raise their children properly and meet their special needs. This category consisted of subcategories of “trying to meet the needs of the child,” “learning about how to meet their needs,” and “gradual development of sources of information.”

3.2. Trying to meet the needs of the child

The first source of information for the parents was healthcare team members, such as physicians, nurses, healthcare personnel, and other informed professionals. However, most families did not confine their information sources to healthcare teams and tried to communicate with other families with the same problem. They also made contact with rehabilitation centers to broaden their information scope.

A mother, self-reported age of 53 years, said: “When my child was a few months old, I met a woman in the neighborhood who suggested taking my child to a rehabilitation center. She said they would teach my child and would work with her. They also did speech therapy. So, I went to register my child at the given center.”

3.3. Learning about how to meet the needs

Sustained efforts were made by the families to learn about the needs of their children and how to meet them. A mother aged 45 years noted: “I attend rehabilitation, speech therapy, and occupational therapy sessions with my child to help her learn better and also to improve her life skills.”

3.4. The gradual development of information resources

The sources of information were gradually developed via the Internet and virtual spaces to meet the needs of children with DS. A mother aged 36 said: “I am so interested in broadening my knowledge about DS, so I can help my child better. I searched the Internet to learn about this disorder.”

3.5. Paying attention to children's healthcare needs

This category indicated that families gradually realized the development of other illnesses and vision, hearing, speech, mobility, heart, thyroid, and psychological disorders in their children. This category consisted of subcategories of “treatment of physical problems and psychological disorders” and “paying attention to prevention.”

3.6. Treatment of physical problems and psychological disorders

The families found that their children needed extra care, which could add to the children's physical and mental health problems if not addressed.

A mother aged 46 stated: “if I do not practice good hygiene and my child gets sick, the whole family will undergo a lot of pressure.”

A mother aged 36 stated: “My child has many physical problems, such as lacrimal duct obstruction, cataracts, hyperopia, diabetes, and hyperlipidemia, and there is a need for numerous treatments and surgeries to address such problems. Therefore, my child needs specialized healthcare services; otherwise, the child's physical health condition will exacerbate increasing the family burden.”

A father aged 56 said: “For a while, my son was aggressive, and we were very worried. So we went to a psychiatrist who gave us some recommendations for this problem. We followed them and my son's aggression got better.”

3.7. Paying attention to prevention

The participants paid special attention to maintaining the children's health and prevention of physical problems and psychological disorders.

A mother, aged 45, said: “My child is disabled. I pay attention to his nutrition, vaccination, and healthcare needs. I follow the caring process completely. He is constantly visited by physicians. I pay attention to his personal hygiene. When he is healthy enough, I feel more relaxed.”

A mother aged 53 said: “My child is prone to diabetes, hyperlipidemia, and obesity. So, I started a diet and he lost some weight. Now, I do check-ups once a year because he is also subjected to thyroid disease.”

3.8. Concentration on spirituality

The participants believed that their spiritual and religious beliefs played a fundamental role in adaptation with the conditions of their children with DS. This category consisted of subcategories of “belief in divine providence,” “prayers for peace” and “caring as worship.”

3.9. Belief in divine providence

The participants considered the birth of their child as divine providence, foreordination, and trial. They believed that the acceptance of divine providence and striving to succeed in divine trials strengthen the foundations of the family and spread peace through it.

A mother, aged 36 years, said: “Maybe God has loved me to give me this child. He wants to reward me in this world and the next world if I keep and raise this child. I can accept and continue this situation better.”

3.10. Prayers for peace

Along with this deep spiritual belief, worship in the form of prayer and reading the Holy Qur’an reduced and eliminated the feeling of fatigue in them and consequently sharpened their sense of calmness.

A mother, aged 51, said: “Whenever I get tired and feel that I am under pressure, I say prayers and I pray for my child and my family and even all patients, and I ask God for well-being and safety.”

A sister, aged 18 years, stated: “When my father feels that he is under pressure, he prays and reads some pages of the Holy Qur’an and then prays for all of us, asking for well-being and eventually for goodness to all of us.”

3.11. Caring as worship

Despite all difficulties, the spiritual beliefs of the participants made caring of children with DS a more pleasant task associated with a sense of inner satisfaction, which could only be compared to worship.

A sister, aged 14 years, said: “This child is pure and innocent. When I am spending time with him, I have the impression that 1 of God’s angels is with me; whenever I do something for him, I have a spiritual feeling. I feel pleased. Being close to an innocent person makes me have peace of mind. I have sometimes experienced such conditions in Ramadan (a holy month of Muslims).”

A father, age 47 years, stated: “Some people may think that having such a child is really difficult, but I firmly believe that God pays special attention to my life just because of this child, and that is why I see looking after this child as an act of worship.”

3.12. Teaching socially appropriate behavioral skills

Teaching socially appropriate behavioral skills to children with DS included educational measures that could shape more appropriate behaviors in them, improve their values and status

in society, and decrease the stigma of DS for both the children and their families. This category consisted of subcategories of “teaching socially appropriate manners to children,” “Exhibiting appropriate behaviors by family members,” and “role-modeling for children and others.”

3.13. Teaching socially appropriate manners to children

The participants’ considerable efforts to teach socially appropriate manners and principles to children by various methods, such as verbally encouraging proper behaviors and preventing inappropriate behaviors. A mother, aged 43 years referred to the people’s prejudices toward children with DS, and her efforts to challenge these prejudices and said: “I have taught my child how to respect the elderly and greet them. I also remind him not to fight with other kids outside the home and not to say bad words. Whenever I see good behavior from him, I encourage him and give him some points. I have made an inspiring card for him and put a star on it.”

3.14. Exhibiting appropriate behaviors by family members

The participants played the role of individuals who respected ethical principles in front of their children to teach them about the importance of ethical practices. A father, aged 52 years, said: “I do not play obscene jokes or immoral works in the presence of a child.”

3.15. Role-modeling for children and others

The parents tried to provide appropriate behavioral role models for their other children, relatives, and society to teach them how to interact with children with DS.

A mother, aged 51 years, said: “My spouse and I have tried to be a good role model for our family and society. We tried to teach them how to properly treat children with DS through our actions and behaviors. For example, we never disrespect our child, we express our love, and we also treat him as a normal child.”

A mother, age 53 years, stated: “My spouse, I and his sister play with him as a group to show him some correct behaviors. We normally ignore his inappropriate behaviors and words to reduce the likelihood of their repetitions; instead, we use correct behaviors or words to teach him how to behave properly, how to talk, how to behave in similar situations.”

3.16. Efforts to increase self-reliance in children

This category showed constant striving and persuasion to empower the families and grow independence and self-reliance in the children with DS. This category included subcategories of “personal hygiene training,” “assigning personal affairs to the child,” “teaching social interactions,” “giving the power of selection to the child,” and “compensation for insufficient professional support by parents.”

3.17. Personal hygiene training

One of the strategies to increase self-reliance in children was teaching them personal hygiene skills.

A mother, aged 36 years, said: “She follows personal (hygiene) routines, such as bathing, brushing, washing hands before and after meals. I have gradually taught her all these (skills).”

3.18. *Assigning personal affairs to the child*

The participants helped the children to make them independent in their personal affairs. A mother aged 53 years, said: “Of course, I taught skills to her and she became gradually independent. Now, I let her do some simple chores, such as dress herself, eating and drinking alone, folding her clothes, sweeping home, or washing dishes.”

A father, aged 35 years, said: “I always try to find ways to help my child and train him to remain independent as much as possible like other kids.”

3.19. *Teaching social interactions*

According to the participants, the lack of adequate information about these children in our society, some interaction issues continue to remain among these children. For example, a mother, aged 36 years, said: “Some of our relatives look at my child as if (he/she) has a contagious disease and do not allow their kids to play with (him/her).” A father, aged 52 years, also said: “People’s views of these children are not appropriate. Some people show pity and compassion, and some others reject them.”

The families tried to solve these problems in different ways, such as teaching social interactions to the child. The participants stated that they attempted to prevent social isolation and expand correct and safe social interactions among their children by helping them to make friends and develop social interactions, especially with healthy peers. For instance, children were taken to the circle of peers and explained about kindness and making friends.

A father, aged 56 years, stated: “I attempted to raise my child like a healthy and normal one. For example, he goes out and plays with normally developed children. I accompany him, encourage him, stand beside him, and ask other children to play with him. I also ask all children to get together in the evening and play soccer. I let my son be the goalkeeper. I introduce him as their friend. So, I help my son be accepted by his peers and I prevent him from being isolated.”

A mother, aged 46 years, said: “I have taught my child how to greet and introduce oneself to others, and how to ask peers to play games with.”

3.20. *Giving the power of selection to the child*

Giving the power of selection to the child contributes to personality development and decision-making skills in children. A father, aged 38 years, said: “Sometimes, I ask about his opinions concerning some activities, especially about his activities, such as his favorite clothes or fun activities.”

3.21. *Compensation for insufficient professional support by parents*

The participants made persisting efforts to find and ask for help from some child counselors and professional healthcare staff of rehabilitation and vocational training centers, and speech therapists. Even though services provided by some centers were limited and ineffective, the families were not disappointed.

A father, aged 55 years, said: “Although occupational therapy in the rehabilitation center was only once or twice a week, and had little effect, I did not abandon it and I took our child to private centers. Any progress, even small, was very important to me. We even accompanied him in the sessions to repeat exercises at home and get better results.”

A mother, aged 45 years, said: “I did not like to take the child to centers for children with special needs. I wanted us to help him become self-reliant, even though it was very difficult and costly.”

3.22. *Development of family support circle*

The family members of children with DS attempted to establish support circles and provide care to help their growth and development. This could share the burden of care among family members and reduce pressures on parents and primary caregivers. This category consisted of subcategories of “increasing family involvement” and “pursuits of support services.”

3.23. *Increasing family involvement*

This category reflects the necessity of more support from other family members to the primary caregivers. The family members realized that it was essential to encourage parents to continue providing care to their children by showing affection and gratitude and reducing their burden. The development of empathy among family members, active participation, and emotional support of parents, along with child participation were some strategies adopted by the participants.

Referring to his awareness of the needs of the primary caregiver, a brother, aged 26 years, said: “as my mother died after the birth of this child, our father needs more help. He also suffers from some illnesses, such as asthma and knee pain. He needs help for taking care of this child. Thus I help him.”

A father, aged 52 years, said: “My family relationships are really good. We support and help each other. We love this child. We pay attention to her needs and we have accepted her (conditions).”

A mother, aged 33 years, stated: “My spouse knows how much I get frustrated looking after this child. My husband loves me very much, he is very fond of me, and he encourages me.”

A mother, aged 53 years, said: “My spouse is really helpful to me in childcare. For example, when he is at home, he assumes the responsibilities for cleaning and bathing the child.”

A mother, age 53 years, stated: “I always explain my child’s physical and mental problems to my other children and remind them that he needs extra care, and they also help as they can. My daughter usually teaches school lessons to her brother and plays with him not to get bothered.”

A brother, age 17 years, stated: “I try to help with caring my brother to reduce pressures on my parents and give them time to get some rest and feel at peace.”

3.24. *Pursuit of support services*

This subcategory reflects efforts made by the participants to get access to and use community services to improve their children’s capabilities. The use of services, such as speech therapy and occupational therapy, assisted the children with the development of practical and communication skills and also gradually reduced pressures on the parents. To help children and compensate for their illnesses and disabilities and to improve their quality of life, the participants sought care from healthcare services.

A mother, aged 45 years, stated: “Twice a week, I take him for occupational and speech therapy. In occupational therapy, she plays some sports and does painting. She has improved much following such therapies.” A mother, aged 51 years, also said: “When my daughter was born, I was very upset and I did not

know where to go and how to track her progress. I searched a lot, and ultimately I found a speech and occupational therapy center.”

However, the available support services were insufficient, and the families still needed more support from public organizations. A mother, aged 45 years, declared: “I have devoted my health to take care of this child. Now, I suffer from herniated disk because of supporting my child. Parents need more support from the health centers and organizations, but unfortunately, neither of them provides the child and parents with support.”

A mother, aged 53 years, talked about the problems she had to meet the needs of her child with DS and the necessity of receiving help from support centers: “The problems of these children are too much. The family alone cannot carry all responsibilities. We need some healthcare centers to help us and teach us how to determine and satisfy our children’s needs. However, the available support services are not enough.” Mentioning the same problem, a mother, aged 33 years, stated: “but if I don’t refer to them, no one comes to us.”

4. Discussion

The present study explored the experiences of families of children with DS and shed light on their coping styles. Although the birth of a child with DS may make families shocked, upset, and frustrated,^[43,44] the families in this study left this critical stage behind and adopted various coping strategies to deal with their children’s condition. Moreover, the categories and subcategories identified were not substantially different for mothers, fathers, and siblings. Iranian parents typically adopt similar spiritual coping strategies.

Searching for information, as the most significant coping strategy, assisting them to understand their children’s needs, finding appropriate ways to meet them, and have peace of mind. Although the parents’ primary source of information is medical and nursing teams, the healthcare providers focus mainly on illness and treatment rather than family-centered care. Therefore, a deeper insight into the psychological and social determinants of health of families of children with serious or chronic illnesses is needed.^[17] The social determinants of health is acknowledged as the structural conditions that affect the health status of individuals and populations. Social determinants are shaped by political systems, resources, and value systems. Unequal distribution of wealth, power, and resources at international, national, and local levels produces health inequities or avoidable differences in health status. Today, these factors are widely recognized as more important determinants than biological mechanisms of disease prevention and treatment.^[32]

The scope of information sources gradually expanded to acquaintances, the Internet, and social networks. These information sources built up their strength in accepting their children’s health conditions, meeting their needs, developing unique support sources, and providing facilities and services required to raise their children. The crucial needs of the families of children with DS encouraged them to participate in educational seminars and panels on DS, read educational brochures and books, talk with peer families, and attend vocational training sessions.^[22] A study in Thailand showed that parents of children with DS were constantly learning from healthcare educators. They were seriously seeking to learn the methods of mental stimulation in children and trying to become familiar with different specialized community support sources via close interactions with the

healthcare systems.^[45] It enabled these families and parents to obtain greater skills and adapt to daily life schedules and management of childcare.^[36] A study on families with a disabled member showed that enhanced knowledge helped them broaden their developmental skills, such as communication, confidence, happiness, and adaptation, instead of focusing on problems. It also helped them with the restoration of balance at the family level and improvement of their quality of life.^[13] Families’ attention to the physical and mental health of their children with DS also helped them reduce physical and emotional pressures.

Moreover, the innocence and purity of children, along with spiritual factors facilitated the acceptance of children with DS. Some studies conducted in Iran and other Eastern countries have further demonstrated that spirituality can increase families’ adaptation with sufferings, develop their mental comfort, reduce their anxiety and care-related stress,^[46,47] and improve their quality of life^[48] and life expectancy.^[49,50] Our findings highlighted the role of spirituality and religious beliefs in families’ acceptance of their children’s conditions. The better adaptation of our participants might be attributed to their religious beliefs derived from the verses of the Holy Qur’an and hadiths of Shiite Imams. For example, according to a saying of Prophet Muhammad, anyone who cares for a patient 1 night will be in heaven with Prophet Abraham. A hadith from a Shiite Imam says, 1 night of caring for a patient is worth as 70 years of worship. Moreover, Qur’an pays great attention to patient care and salvation: “whoever saves 1 – it is as if he had saved mankind entirely.” The lifelong spirituality of a Muslim can also be seen in a poem by Rumi (the great Muslim poet): “All day I think about it, then at night I say it. Where did I come from, and what am I supposed to be doing? I have no idea. My soul is from elsewhere, I am sure of that, and I intend to end up there”. This poem clearly illustrates that spirituality has a high status in the life and adaptation of Iranian people including the families participated in this study.

Teaching socially appropriate behavioral skills to the children with DS and facilitating their social interactions were among the main coping strategies adopted by the participating families in this study. Earlier studies reported that the stigma of DS can isolate both the children with DS and their families,^[51] mostly due to the people’s prejudices about the inappropriate behaviors and slower cognitive development of these children.^[52] However, the efforts of our participants in teaching socially appropriate behavioral skills and facilitating their social interactions helped them decrease problems related to the stigma. Phillips et al investigated parenting styles among the mothers of children with DS and reported that such mothers in comparison with those of normally developed children used less authoritative and reasoning styles, and verbal aggressiveness. They also adopted more permissive parenting styles and were indifferent to their children’s inappropriate behaviors, which could increase the parents’ levels of anxiety about their children’s ethical and behavioral abilities.^[53] Despite treating with indulgence to improper behaviors, the participants in this study exercise further supervision and showed a higher level of sensitivity to the behavioral education of their children with DS using games, demonstration, and role modeling.

Efforts to increase the self-reliance of children with DS and develop their developmental skills, and achieve the greatest personal independence in their daily routine activities were emphasized in this study. The gradual transfer of handling personal affairs, vocational training, and speech therapy were

adopted by the participating families to increase the self-reliance and independence of their children with DS. One sign of acceptance of children with DS in a family is to see whether they are treated like normally developed children.^[22] Therefore, efforts made by families to increase the self-reliance of children suggest the recognition of and belief in their human and personal capabilities. This finding was consistent with the results of a previous study, in which families with children with disabilities tried to use certain problem-solving strategies to educate their children.^[15] Self-reliance in children with DS can reduce parental and family care burden,^[44] and mitigate parental concerns about their future life.^[54] Rassafiani also believed that early measures taken by parents to develop independence in children with DS through the development of self-help, sensory-motor, perceptual-motor, and emotional skills could even result in independence in adulthood.^[22]

Another strategy adopted by the families to cope with the presence of children with DS was the involvement in various activities to show love, emotional support, and gratitude to primary caregivers, encourage them to continue the difficult caring responsibilities and reduce associated physical and mental pressures on them. It has been reported that parents of such children suffer from feelings of guilt, abandonment, disappointment, unhappiness, anger, and embarrassment, and also an unhealthy obsession with the health of their ill children and other family members.^[43,44] However, appreciating the efforts of caregivers and providing more support to them can develop a sense of solidarity and meaningfulness, and improve their life expectancy, control over the situation, and ability to confront with difficult living conditions.^[37] According to the participants in the present study, using available social support services could empower children with DS, reduce pressures on families, and increase their optimism and hope. However, the available support services seem to be insufficient and therefore the families expressed their need for more support from the healthcare providers such as family nursing. The availability of support services can reduce the negative emotions of families.^[43] Earlier studies also reported searching for social support as a coping strategy adopted by families.^[15,39] Families who do not have access to support services or are not able to pay for these services have fewer opportunities to carry out health promotion behaviors while more problems in raising their children with DS. Therefore, health care authorities are responsible to augment the existing support services and increase the number and extent of services available to the disabled children and their families, including those having a child with DS. In particular, community and home care services can be effective for assessing the health of the children and their caregivers, providing education and advice on the importance of maintaining health, and also for providing support.^[23] However, nurses in Iran have a low presence in society and are mostly working in hospitals. Although there are undergraduate and postgraduate programs in the field of family and community health nursing and childcare in Iran, they play a minor role in the community and health policymakers should address this issue.

Although there are several community healthcare centers in rural and urban areas, their focus is mainly on the health and development of normally developed children; whereas, there are not many similar services for children with impaired development. Nonetheless, social support can increase the emotional health and resilience of their parents.^[39,55]

Despite the deficiencies in social support services, participants tried to develop the family support circle to support the primary

caregivers of children. Supports received from the family members, relatives, and families with the same conditions can help caregivers with better adaptation, empower parents, and induce them the feeling of being competent to deal with problems.^[14]

Our findings are consistent with the transactional model of stress and coping.^[56,57] In this model, the interpretation of a stressful event is more important than the event itself. According to this model, there are 2 main types of coping:

- 1) problem-focused coping, which is directed on reducing environmental demands or increasing personal resources, and
- 2) emotion-focused coping, which is concentrated on controlling emotional responses to a stressful situation.^[58] Problem-focused coping strategies include all the active efforts to modify or eliminate the sources of stress (i.e., actively planning, getting help and advice from others, and seeking treatment, intervention, information, and social support). Emotion-focused coping involves attempts made to regulate the emotions evoked by the occurrence of a stressful event and can be considered active (accepting the fact that it has happened, receiving emotional support from friends and family, positive reframing or trying to see it differently, praying, meditating, using spirituality, and respite) or avoidant (self-distraction).^[59,60]

Out of the 6 main strategies used by the participants in this study, 5 strategies can be categorized as problem-focused and 1 as active emotion-focused (i.e., concentration on spirituality). This finding showed that our participants could suitably cope with the problems of having a child with DS over time.

Studies have shown controversial results about the more efficient coping strategies. Problem-focused coping is generally viewed as an adaptive coping style while emotion-focused strategies are supposed to be associated with increased cumulative health risk in caregivers.^[59] However, some studies have reported that active emotion-focused coping is typically adaptive while avoidance strategies are associated with negative consequences.^[59,61,62] Some researchers also believe that people who adopt a wide range of coping strategies are more likely to successfully cope with stressors.^[63] Studies on parental coping also showed a tendency to shift from problem-focused coping to emotion-focused coping strategies over time.^[64] Many studies also revealed that coping strategies are context-dependent. Asian caregivers tend more to use collectivistic problem-focused coping methods, such as seeking treatments, gathering help from support networks, and changing inner perceptions^[59,65] while Western parents focus more on self-focused individualistic coping strategies.^[65,66]

Since the present study only focused on the coping strategies adopted by families of a child with DS, their other experiences relevant to this problem were not fully covered. Moreover, we recruited our participants among those whose children were registered in the welfare and rehabilitation centers of Bushehr City. The results might not be fully generalizable to families who did not enroll their children in ISWO or lived in rural areas. Therefore, further studies are recommended to investigate the coping strategies of families who have no relationship with ISWO, live in rural areas. Moreover, we mainly used semi-structured interviews to collect research data. However, further studies with a focused group and observational methodologies may help researchers explore deeply the experiences and coping strategies adopted by the families of children with DS.

Furthermore, we did not investigate the experiences of the children with DS and thus future studies are recommended to fill this gap.

5. Conclusion

Although the burden of caring for and raising a child with DS was heavy, these families could effectively cope with its problems and tried to bring up their children properly. However, the family's adaptability depended on the support available. The findings of this study have important implications for health professionals, researchers, and policymakers in providing services to children with DS and their caregivers. Family members of such children should deal with many problems in managing these children. Therefore, healthcare authorities and social support organizations should provide them with more effective supports.

This study highlighted the need to develop intervention programs and professional supports to continually provide these families with more supports for promoting their health, reducing their stress, and improving their adaptability to the problems of having children with DS. Family nurses, if available, can provide families with better and ongoing health education and counseling. They also can provide child-related education at home, and implement regular family-centered home visits, and train the families on how to handle the problems associated with DS. Educational interventions should also be made to empower family nurses and other health care providers currently working in health care centers and enable them to respond better to the challenging situations of families with children with DS. Moreover, more rigorous studies should be conducted to assess the caregivers' lives and improve home-based programs.

Acknowledgments

The authors would like to thank the Research Deputy of Tarbiat Modares University for providing the necessary conditions for the implementation of this project. All participants who contributed to the production of this paper, especially the families of children with Down syndrome, are also thanked.

Author contributions

RG, FA, and SMKHK participated in the design, execution, and analysis of the study, as well as the writing of the manuscript. All authors read and approved the final manuscript.

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