

# Casplan Journal of Pediatrics

**Babol University of Medical Sciences** 

e-ISSN: 2383-3106



# Life Experiences of Mothers of Children with Down Syndrome and Comparison of Parents' Emotional Cognitive Strategies Using Mixed Research Methods

Robabe Salehi <sup>1</sup> , Azra Mohammadpanah Ardakan <sup>1\*</sup>

1. Department of Psychology, Faculty of Humanistic and Social Sciences, Ardakan University, Yazd, Iran.

Address: Ardakan University, Ayatollah Khatami Blvd., Ardakan, Yazd, 95491-89518, Iran.

Tel: +98 3533900000 Fax: +98 3532248384 E-mail: azramohammadpanah@ardakan.ac.ir

**ABSTRACT** 

#### Article Info.

# **Article type:**

#### Research Article

Received: 31 July 2024 Revised: 3 Nov. 2024 Accepted: 10 Nov. 2024 Published: 26 Jan. 2025

# **Keywords:**

Cognitive Emotion Regulation, Down syndrome, Lived Experience, Mothers, Parents **Background and Objective:** The aim of this study was to investigate the life experiences of mothers of children with Down syndrome (DS) and to examine parents' cognitive-emotional strategies against stress.

Methods: A sequential exploratory method was chosen in this mixed-method study. In the qualitative phase, ten mothers with DS children were selected to be interviewed using purposive and phenomenological methods. The interviews were analyzed using the Colaizzi method. In the quantitative phase, 32 questionnaires on cognitive emotion regulation by Garnefsky (2006) were completed by the parents of DS children and 34 questionnaires by the parents of normal children. The results were then analyzed using the ANCOVA method. Findings: Four main categories were identified in the qualitative phase: mothers' emotions over time, problems over time, efficiency and performance experiences, and management of problems. The quantitative results showed that the mean and standard deviation of blaming others was 7.98±0.56 in the group of parents of DS children, and 9.95±0.54 in the group of parents with normal children. Moreover, the mean acceptance was 14.66±0.56 in the group of parents with DS children and was 12.84±0.55 in the group of parents with normal children. In other words, blaming others and acceptance were lower (p=0.05) and higher (p=0.03) in the group of parents with DS children than in parents with normal children, respectively. Conclusion: It can be concluded that the group of parents with DS children achieved a greater increase in cognitive emotion regulation skills compared to other parents.

#### **Cite this Article:**

Salehi R, Mohammadpanah Ardakan A. Life Experiences of Mothers of Children with Down Syndrome and Comparison of Parents' Emotional Cognitive Strategies Using Mixed Research Methods. Caspian J Pediatrs March 2024; 10: e15.



<sup>\*</sup>Corresponding Author: Dr. Azra Mohammadpanah Ardakan;

# **Introduction**

congenital Down syndrome (DS) is a chromosomal disorder occurring equal in proportions in different communities, regardless of ethnicity, or geographic location [1]. With a prevalence of approximately 1 in 750-800, this disorder results in varying degrees of intellectual disability [2]. Atypical brain development and the resulting intellectual disability originate in the fetal period [3]. DS occurs when a person has a complete or partial extra copy of chromosome 21 [4, 5]. DS individuals typically have a variety of medical and congenital aberrations and require ongoing care [6]. DS leads to many different phenotypes including learning difficulties, Alzheimer's disease, and problems with motor skills like abnormal gait and poor fine motor skills [7]. DS persons need ongoing care at home and to be referred to physicians and other specialists [8]. Having a child with DS can affect the life quality of parents. Mothers are likely to experience gradual pressure and stress, leading to emotions negative like loneliness, defenselessness, sensitivity to the behavior and words of others, emotional fatigue, and chronic grief [9]. They may become isolated themselves and abandon all expectations, roles, and identities [10].

As mothers with DS children increase their tolerance, they will change their cognitive schema regarding their children's disabilities. This helps mothers to accept their children's disability and reduce stress [11]. Changing the feelings and attitudes of parents with exceptional children about their environment and lives can promote their mental health, hope, and problem-solving skills [12]. Most studies concentrate on the life experiences of disabled children. Karami Nejad et al. (2020) focused specifically on mothers with DS children [13] and found that parents' responses to the diagnosis varied, ranging from complete acceptance to lack of acceptance of the special needs of DS children. The way emotions are expressed can influence the environment and emotional behavior [14]. To date, several studies have been conducted on the experiences of mothers with DS children, but the different ways of coping with stress and mental stability of these parents have not been discussed. Therefore, the present study addresses such a gap by using combined research methods, mothers' lived experiences, and parents' cognitive regulation of emotions [15].

Acknowledging mothers who have experienced parental stress is important in that it not only affects their psychological well-being but also the rehabilitation and growth outcomes of their children [16]. Moreover, studying the long-term effects of parents' coping with stress is of great importance as it can provide valuable insights, especially for intervention purposes [17, 18, 19].

The aim of this study was to investigate the life experiences of mothers with DS children as well as report on how they cope with their children and how they manage stress in both mothers and children..

### **Methods**

The study population included parents with DS children. Due to the greater coherence and availability of data, the community of parents with DS children <15 years old in Najaf Abad City was studied.

The inclusion criteria were 1) parents living in the same house with their (DS) child, and 2) parents with DS children who wish to participate in the study. The exclusion criteria were 1) refusal to continue to participate in the present study, and 2) parents whose child had a disease other than DS.

Qualitative sample: The sample included 10 mothers of DS children from Mehr Center (the only educational center for DS children in Najaf Abad) with purposive sampling.

Quantitative sample: The sample included 66 parents (32 parents with DS children from Mehr Center, and 34 parents with normal children in Najafabad).

In the qualitative method, the instrument was the semi-structured interview. Due to COVID-19, the 20-45-minute interviews were conducted by telephone at home and recorded. The mothers were asked to talk about their experiences and feelings since the birth of their child and when they learned that their child had DS, and to tell us about their child's injuries and illnesses as well as the experiences and challenges of living with their children (they were assured that their information

would remain confidential). The audio files were listened to several times and transcribed verbatim. The Colaizzi method based on descriptive phenomenology was used to analyze the data.

To check validity, the data from each interview was shared with the participants after analysis and the necessary corrections were made based on their views. Moreover, the findings related to the main categories and subcategories were reviewed and modified based on the relevant experts and professors. Due to the conditions for conducting the questionnaire (COVID-19), the questionnaires were sent to the participants virtually and all of them were returned after completion.

The questionnaire used in the current study was the Cognitive Emotion Regulation Questionnaire (CERQ) by Garnefsky [20]. The scale comprises 36 questions assessing the following nine cognitive self-blame, acceptance, strategies: obsessive ruminating (thought concentration), positive reinterpretation, focusing on plans, relativization, catastrophizing, and blaming others [21]. The questionnaire assesses the cognitive emotion regulation strategies on a five-level point from 1 (never) to 5 (always). Higher scores indicate that the person uses more cognitive strategies [22]. Jafarpour Mamaghani et al. examined the factor-analytical validity of the shortened version of the questionnaire. They have concluded that the Persian version of the questionnaire has adequate reliability and validity and can be used for the Iranian population [23].

#### Results

The results were divided into four main categories: mothers' emotions and problems (four times: before pregnancy, during pregnancy, after childbirth and today), mothers' efficiency and practical experiences, coping with problems and management of problems. Tables 2, 3 and 4 present the corresponding results. Before that, Table 1 illustrates the demographic information of the parents.

Emotions: Emotions are an unconscious phenomenon. In psychological terms, the term "emotion" is a generic term that encompasses arousal, feeling and mood. Emotions are usually defined as a positive or negative evaluation of a

topic, behavior or idea with severity and activity dimensions. A tendency is present when a person continuously perceives or repeats a certain topic [24].

The main category of maternal emotions was divided into four subcategories: before, during and after pregnancy, and in the present.

- 1. Ignorance, negative attitude and fear are among the subcomponents of the mother's feelings before pregnancy. The fear is possibly due to a negative attitude towards the unfit child. The negative attitude could also be due to a lack of awareness or low awareness of the disabled child. Statement of a mother: "During the 15 years that I did not have a child, my relatives and friends always told me that I should see a doctor for treatment. However, I replied that I would not go because I knew God would give me a sick child. That's what I always said".
- 2. The emotions during pregnancy consist of different emotional states, including good feelings, normal feelings, and stress feelings, which probably stem from negative thoughts. Mother's description (c): "It is normal that a pregnant woman's behavior changes. I was very depressed. I had a lot of negative thoughts. I was afraid of having a DS child. I dreaded it. I do not know, but it inspired me because I always thought there was something wrong with the child".
- 3. In the third subcomponent, the terms "shock", "disbelief", "confused", and "bewildered" may seem to be the same. However, when these terms appear in a person, they show different feelings and thoughts in the person. When mothers learn of their children's problems, these are the first feelings they experience. Those who have had their first child after many years of infertility (7 years, 15 years, ...) experience greater shocks. Some mothers may even lose their temper and show their anger by killing their child or committing suicide. They had feelings of hatred towards the child who had stimulated them. In fact, sadness is a feeling that all mothers experience and it can last for years even if the mothers accept the condition of their children. Mother (c) describes her state after learning that her child has DS: "I did not know what to do with the child. What would happen now? I just stared at him and thought about this problem".
- 4. In the fourth subcomponent, which refers to the mother's present emotions, the negative feelings

gradually change into positive ones, such as love for the child. Some mothers also refer to their dependence on their children. Some others even consider their child precious and sacred and feel happy to have the child. They have taken responsibility for their child and feel that God has made them patient to take this responsibility. Some mothers also compare their children with other weaker and disabled children and feel more satisfaction. For example, mother (h) said: "I thank God that his father and siblings love him. They are lovely. I do not know if you have ever dealt with them, they are really nice and lovable".

In the second case, the aim of the study was to investigate the problems of the mothers before pregnancy, during pregnancy and the problems in the present.

- 1. Some mothers who suffered from a physical illness or infertility before pregnancy had this mental worry that their illness and the associated treatment process would cause DS in their child. For example, mother (e) stated that: "I could not have a child for 15 years. I went to a glandular doctor who told me I needed surgery. I did and had my thyroid completely removed in the first month of the year. Then, in the second month, I got pregnant. I do not know if the anesthesia or the scans I had affected my baby".
- 2. In the second secondary subcomponent, most of the mothers complained that the specialist was not able to diagnose their children's problem even though they were referred for timely screening, tests and sonography. Other problems that the mothers had experienced (besides their stress) during pregnancy were specific pregnancy illnesses, problems with the embryo and premature births. For example, mother (c) stated that: "The blood test had indicated it but the specialist did not notice it. Later, when I took the test result to the genetics center, I was told that the blood test indicated the problem".
- 3. In the survey conducted in this study, all mothers became aware of DS in their children after birth. They were all dissatisfied with the way the nursing staff informed them about the problem. The mothers had to deal with their children's problems after discharge from the hospital and the behavior and look of others increased their problems and sadness. They either had to stay at home because of

the children's physical problems. Mother (d) commented as follows: "It was very hard for me. I did not go out anymore and I did not work either. I was always with my child".

4. The mothers' problems at the time of the interview were physical problems that were the continuation of physical problems in childhood that could not be cured or had been treated unsuccessfully. Additionally, there were also speech and behavioral problems in the child. Most mothers had focused on speech problems. After that, family and economic problems, fear for the child's future, and behavioral problems of school officials in performing their duties were other problems highlighted by the mothers. For example, mother (b) stated: "I feel nervous when I see other children are healthy. My child wants to play with them and talk to them, but he cannot. It is hard for him too".

The services that most mothers have provided for the survival, safety, growth and progress of their children have been summarized in a category called maternal efficiency and performance experiences. It includes secondary components such as caring for the child, supporting the child at gatherings, attempting to develop the child's movement and speech, helping with the child's education and supporting the child's upbringing. Example mother (t): "I was told to take him to occupational therapy and speech therapy. I started when he was seven months old".

The last part of the qualitative analysis examined how the mothers dealt with the problems and stress of having a DS child. First, they stated that the real reason for their ability to deal with the problems was their trust in God and the goodness of their mother. Then, some mothers expressed that the support of others, especially family members, was also effective. However, some others were disappointed with the support from others and declared that selfreliance was an important factor for them to cope with their problems. They became more hopeful when they saw their children making progress and when they compared their children with other weaker and disabled children. They could ignore the annoying behavior of others and accept the fact that it was God's wish to have such a child. Example mother (c): "Now I only trust in God. It is His own will and He will help me".

Now to the quantitative phase: The data were analyzed by the questionnaire and its 9 subscales using SPSS 26 on two descriptive and inferential levels. Before analysis by ANCOVA, the normality and homogeneity requirements for the variance were checked. When these two assumptions were confirmed, ANCOVA was used to make a more precise comparison between the two groups and also control the intervening variables. The child gender was controlled in the present study [25, 26]. Table 5 illustrates the demographic information of the parents and the analysis of the results.

Table 6 shows that the significant level in the scales of blaming others and acceptance is <0.050, representing that the two groups differ significantly in the test of cognitive emotion regulation in the two above-mentioned scales.

Table 7 indicates that the mean blaming others is lower in the group of parents with DS children  $(7.98\pm0.56)$  than in the group of parents with normal children  $(9.95\pm0.54)$ . Furthermore, the mean acceptance was higher in the first group  $(14.66\pm0.56)$  than in the second group  $(12.84\pm0.55)$ . In other words, blaming others and acceptance were lower (p=0.05) and higher (p=0.03) in the group of parents with DS children than in parents with normal children, respectively.

#### **Discussion**

This study aimed to investigate the life experiences of mothers with Down syndrome (DS)

children and compare the cognitive-emotional strategies of parents with DS children versus those with typically developing children.

In the qualitative analysis, the first category identified was the mother's emotions, including 4 secondary categories and the following subcategories.

1-Emotions before pregnancy (ignorance, negative thinking and fear).

2-Emotions during pregnancy (appropriate, normal emotions, negative thoughts and stress).

3-Emotions after learning about the child's problem (shock, disbelief, bewilderment, confusion, nervousness, sadness, hatred, boredom, irritability and acceptance).

4-Mother's emotions in the present (interest, happiness, love, appreciation, sacredness, responsibility, patience and perseverance, dependence, satisfaction and perspective taking).

Some studies have been done on the subcategory of the third secondary category. The results indicate the negativity of maternal emotions during this period. For example, Karami et al. (2019) concluded that all parents experienced moments of sadness and despair. Nelsongoff et al. (2013) citing Naghdi et al. [27] found that parents have many negative feelings like worry and guilt for their child after receiving a diagnosis of DS.

The last category showed that these emotions had become more positive compared to early knowledge of the child's problem, which is consistent with the study of Skotko et al. [28].

	Table 1	. Demogra	phic in	formation	of the	parents
--	---------	-----------	---------	-----------	--------	---------

Mother's	Child's age	Child's gender	Number of children					
Mother A	14	boy	2					
Mother B	5	girl	2					
Mother C	7	girl	1					
Mother D	12	boy	3					
Mother E	7	girl	1					
Mother F	8	boy	2					
Mother G	10	girl	3					
Mother H	12	girl	5					
Mother I	7	boy	2					
Mother J	6	boy	1					

Table 2. Mother's emotions before pregnancy, during pregnancy, after birth and awareness of the child at the present time

	g -		resent time
Main Components	Secondary	Sub-	<b>Primary concepts</b>
Components	components	Components Unawareness	I was totally unaware of sick child, DS, autism and the like.
	Mother's emotions before pregnancy	Negative	I just said to God that please give me a companion. I never
	Aother' motion before regnanc	thinking	asked Him to give me a healthy child.
	er er pre	Fear	I was afraid of having a DS child.
	ons	Good	I felt better about this child than my other children.
	motii	Normal	I went to the doctor every month and had no particular problems.
	Mother's emotions during pregnancy	Negative thinking	I had a pregnant thyroid. I felt like the baby would have been retarded otherwise.
	Moth	Stress	My pregnancy was stressful. I had a lot of stress in my pregnancy
	-	Shock	I was shocked when I was told the story.
	th ano Jem	disbelief	I could not accept the fact that my child had Down. I was very depressed.
	bir	Puzzled	I just looked at him and thought about him.
	Mother's emotions after birth and awareness of child's problem	bewildered	I did not know what he would become of him and what I should do with him.
me	ons	Nervous	I was very nervous.
ver tii	emoti ess of	Sad	When I was home alone and my other children went to school, I took this child and cried.
ls o	r's æne	Hatred	I did not want this child at all.
tior	the	Stimulation	I was on the verge of killing myself and the child.
s emo	Мо	acceptance	I told myself that it was God's will and there was nothing I could do about it.
Mother's emotions over time	ime	Interest	This child is my world. I love her! Without Fatemeh, I am a dead person.
Σ	nt t	Prosperity	I owe everything I have achieved in my life to this child.
	ese	Love	I love her too much as she is both kind and lovable.
	at pr	Being valuable	I am proud to have such a child. I hold my head high and say what is wrong with my child?
	child	Holiness	My son is not to bleme. He is innocent. He is very lovable.  Thank God.
	Mother's emotions toward the child at present time	Responsibility	We are responsible for this child and as his parents, we will fully support him.
		Patience	I am a nervous person. I am not patient. I say to God, how could you give me patience for this child?
	otions	Dependence	I am very attached to this child. Even if he does not sleep, I can not sleep either. That's how attached I am to him.
	her's em	Satisfaction	He is really kind, good and compassionate. When I am sick, he says "My dear mother"! He hugs me and brings me fruit, water, medicine, etc.
	Mot	Inspiration	My child is different from the others. I am very hopeful. I am in a good mood.

Table 3. Mother's problems before pregnancy, during pregnancy, after birth and awareness of the child's problems towards the child at the present time

towards the child at the present time						
Main Components	Secondary components	Sub- components	Primary concepts			
	Mother's problems before pregnancy	Physical problems Infertility	Before my child was born, I had a fibroma two years before. I had a surgery. I had also severe anemia.  I could not get pregnant. For the second child, I went to the same doctor as for the first child. I was given the same injections.			
		Lack of diagnosis in screening	To be honest, I did all the tests and showed the results to the doctors too. But I was not told that there was this problem.			
Mother's problems during pregnancy	s problems c pregnancy	Special diseases during pregnancy	When I went to see the doctor, I was told that I had a thyroid. I was asked if I had had the same problem before and I said no. The doctor then told me that it was a pregnancy thyroid.			
	Mother's P	Embryo's problems and precocious birth	Since my pulse and that of the child were not the same, I had the child in the eighth month.			
	h and em	Dissatisfaction from the care personnel	They did not wait to tell me the news after putting the baby in the machine. Because of this shocking news, I could not feed the child.			
	after birtl d's probl	Child's physical shortcomings	When my child was born, I was told that the child had turned black. The child was then put on the machine and given oxygen.  He had too high a heart rate and lung failure.			
Mother's problems over time  Mother's problems after birth and awareness of child's problem	Mother's problems a awareness of child	Mother's problems awareness of child	Dissatisfaction with others	People who saw me outside the house kept saying why did you give birth to the child. I was very sad when they told me to thank God that it was a son. When I reached home, I started crying and told myself that I would not throw the child away even if it was a daughter.		
			Mothe	Mothe	Mothe	Motho
Mothe	ime	Child's physical shortcomings	His heart is big. It has five holes and high pulmonary pressure He is stubborn.			
	be.	present ti	Child's behavioral problems	He does what he wants. The more we insist, the less he listens.		
Mother's problems toward the child at the p		Child's speech problems	Speech problems? No, he has no problem. He walks and does his work, but he can not speak. He only speaks briefly, for example, father, mother, let's go. I know what he means, but others might not.			
		blems toward the c	Economic problems	I did not take him to speech therapy and occupational therapy with my own money. My husband is a simple construction worker. I only sent him to the Mehr Center. But this center is now closed because of COVID-19.		
			blems ta	blems t	blems t	Family problems
	er's pro	Future anxiety	When she falls asleep, I start crying and tell myself that I have no mother and I am unhappy. I wish my daughter was at least not like me. She could have a good future.			
	Moth	Dissatisfaction from school officials	The teacher generally did not care about my child. For example, whenever we were there, the teacher was with another person, not with my child. My child was pushed a few times by other children and blacked out. We stopped going there.			

Table 4. Mothers' experiences of efficiency and performance and how they deal with and control problems

Main Component	Secondary Components	Primary Concepts			
_	Caring the child	Initially, he could not eat anything by mouth. I was told that he had problems swallowing. The first year, I used a tube to feed him.			
and pr	Supporting the child in gatherings	I put good clothes on him. Others say, are these clothes available on the market? I respect him a lot.			
Mothers' efficiency and practical experiences	Attempt to develop the child's speech and movement.	Before COVID-19, I took him to speech and writing therapy twice a week until September. That was very useful and helpful.			
hers' eff ex	Help to develop the child's training	He is very good at brushing his teeth. He even helps me with the housework. If I ask him to fetch something, he does it.			
Mot	Child's educational support	I work with him through virtual classes. I should also spend time playing and coloring with him.			
	Reliance on God	May God give everyone the patience to raise their children and grow up. God has given me the patience.			
	Mother's kindness	I am grateful to God for allowing me to love this child. I thank God for bringing Fatemeh into my life. She is my companion and friend.			
St	Receiving comfort from family members	I have an older child aged 10. He does his work and the younger one helps too.			
.oplen	Others' support and guidance	His coach tells me to be patient because she is intelligent and a nice child. Others comforted me.			
anage pi	Seeing the child's abilities growth	Later she grew up and started to walk. I took her to kindergarten. I saw her abilities. I could relieve my stress and deal with the situation better.			
h and m	Familiarity with other Down children	The Mehr Center was the place that gave me hope I went there for the first time. Other people's children went there too. They all learned and I was very happy.			
deal wit	Self-reliance	Neither our husband nor our family helps us. It is only the mother who should take care of the child. I always comforted myself with these words.			
How to deal with and manage problems	Ignoring the annoying behavior of others	Others looked angrily at the child and said to me, "May God give you patience". I became very angry. But I tried to calm down and told myself that my child was okay and that I was proud of him.			
	Comparison with more disabled children	There are some children the same age as my child, but they can not walk as they have a foot disability. But my child is fine. You can not say that my child has the syndrome.			
	Accepting God's wish	It took me a year to accept that God had given me this child and that I had to look after him.			

**Table 5.Demographic information of the parents** 

Parent of Down Syndrome children				Parent of normal children							
F *	Educational level	F *	gender	F *	age	F *	Educational level	F *	gender	F *	age
3	Under diploma	26	female	5	25-35	3	Under diploma	29	Female	10	25-35
13	Diploma			10	35-40	13	Diploma			10	35-40
4	Higher Diploma	_	1	9	40-45	7	Higher Diploma	_	M-1-	10	40-45
10	Bachelor	0	male	8	55-45	10	Bachelor	3	Male	4	55-45
2	Master					1	Master				

<sup>\*</sup>Frequency

Table 6. ANCOVA of the 9 scales of the questionnaire with the children's gender control

Scales	<b>Total Squares</b>	DF	Mean of Squares	F	Sig.	IF
Positive focus	15.955	1	15.955	1.490	0.227	0.023
Focus on the plan	2.293	1	2.293	0.261	0.611	0.004
Positive reinterpretation	6.841	1	6.841	0.540	0.465	0.008
Putting into perspective	34.782	1	34.782	3.500	0.066	0.053
Self-blame	22.622	1	22.622	1.457	0.232	0.023
Blaming others	62.894	1	62.894	6.254	0.015	0.090
Obsessive thinking	28.449	1	28.449	2.602	0.112	0.040
Catastrophizing	21.573	1	21.573	1.795	0.185	0.025
Acceptance	54.067	1	54.067	1.294	0.025	0.078

Table 7. Analysis of mean and SD of the 9 scales

Scales	DS childre	n parents	Normal children parents		
Scales	Mean	SD	Mean	SD	
Positive focus	13.859	0.581	12.868	0.563	
Focus on the plan	15.830	0.526	15.454	0.510	
Positive reinterpretation	14.895	0.632	14.246	0.613	
Putting into perspective	13.549	0.560	15.013	0.543	
Self-blame	11.119	0.700	12.300	0.678	
Blaming others	7.986	0.563	9.955	0.546	
Obsessive thinking	12.772	0.587	14.097	0.569	
Catastrophizing	9.618	0.615	10.771	0.597	
Acceptance	14.668	0.567	12.842	0.550	

According to their authoritative survey of DS families, of 2,044 respondents, 99% said they loved their son or daughter, 97% were proud of them; 79% felt they had a more positive outlook on life, 5% felt ashamed and 4% regretted having them. Fernandez and Izosquiosa <sup>[29]</sup> also concluded that although the DS diagnosis in a child is unexpected and stressful for the family, the general perception and feeling of the impact of the child on the family is positive. Hemati et al. <sup>[30]</sup> found these results: "DS children are well accepted in their families and are compatible with family members".

The second main category is problems of mothers with DS children, including 4 minor categories and the following subcategories:

- 1-Problems before pregnancy (physical diseases and infertility).
- 2-Problems during pregnancy (failure to recognize the syndrome at screening, special diseases during pregnancy and fetal problems and premature birth).
- 3-Mother's problems after birth and awareness of the child's problems (dissatisfaction with the medical staff, physical inadequacy of the child,

dissatisfaction with the people around and abandonment).

4- Mother's problems in the present (child's physical problems, child's behavioral problems, child's speech problems, economic problems, family problems, fear of the future and dissatisfaction with school staff).

At the beginning of the interview, the mothers talked about the fact that DS was not detected during the screening. Most of them had ultrasounds, blood tests and 3D ultrasounds and complained about the lack of identification and the inability of doctors to make a diagnosis. In the study by Naqdi et al. <sup>[20]</sup>, such a category was considered as lack of knowledge of the specialists. Hemti et al. <sup>[31]</sup> also classified the major family problems of DS children into seven groups: physical, mental and behavioral, social, educational, maintenance, supportive and communication problems.

The third main category, functional experiences and efficacy of mothers with DS children and coping and dealing with problems, includes two secondary categories and the following subcategories.

1- Mothers' functional experiences and efficiency (caring for the child, supporting the child in the

group, trying to develop the child's movement and speech, helping with the child's educational development, supporting the child's education).

2- How to deal with problems and solve problems (trust in God, maternal love, comfort from other family members, guidance and support from those around you, seeing the child's growth and abilities, getting to know other children with DS, self-confidence, ignoring others' liberating behavior, comparison with weaker children, acceptance of God's will).

When analyzing this part, it becomes clear that the parents want to support the child and promote the child's movement and language development as well as support the child's academic development. The result of this support and training is that they help their child to become independent and socialize. These results are the same as Behnam's study [32], representing that both parents and teachers believe that the educational content available has a positive impact and has a high (more than 70%) effect on the independent living skills of mentally disabled children.

The last category deals with problems and coping by mothers with DS children with the following secondary category and sub-categories:

1-How to deal with problems and how to overcome problems (trust in God, maternal love, comfort from other family members, guidance and support from those around you, seeing the child's growth and abilities, getting to know other DS children, self-confidence, ignoring behavior that bothers others, comparison with weaker children, acceptance, and divine will).

The results in the quantitative part were obtained as follows:

In this part of the study, the questionnaires were first analyzed after scoring using

9 scales, positive refocusing, refocusing on planning, positive reappraisal, perspective taking, self-blame, other-blame, rumination, catastrophic thinking and acceptance. The homogeneity of the variances was checked after proving the normality of the data. Then, the parametric test of covariance analysis was used to control the intervening variable. The child's gender variable was controlled in this analysis [26, 27].

After controlling for the child's gender and the covariance analysis, the significance level of the two scales (blaming others and acceptance) was <0.05 and the difference between the two groups in these two scales became significant. When comparing the emotional cognitive regulation of parents with DS children and parents with normal children. According to the mean level of the two groups, the mean level of blaming others in the group of parents with DS children (7.98±0.56) was lower than that in the group of parents with normal children (9.95±0.54); The mean acceptance score in the group of parents with DS children (14.66±0.56) was higher than that in the group of parents with normal children (12.84±0.55). In fact, after a few years, the mothers conclude that no one is to blame for their child's DS. and the attribution of blame to others decreases among them. They also consider acceptance to be the only definitive way to recover from the existing situation and to try to make progress and succeed, which agrees with some studies [33, 9], indicating mothers of healthy children use less problemand emotion-oriented confrontations oriented compared to mothers of children with DS. The experiences of mothers with a DS child show that they see their child as a blessing and trust in God, relying only on God and that they do not have adequate and effective support resources.

#### **Limitations**

The quantitative data were collected using a selfreport questionnaire. As it was not possible in most cases to compare the groups studied, the results should be treated with caution.

#### **Conclusion**

Based on the extracted categories of maternal emotions over time, it is clear that emotions that are complex, ambiguous and negative at the beginning become more balanced over time and demonstrate themselves stably and positively. The interviews conducted with mothers with DS children and the analyses suggested that most of the mothers went through a growth process after the accident. For example, in the main category of postpartum mothers' problems, mothers who were dissatisfied with the treatment staff ignored the annoying

behavior of others over time and tended to seek advice and support from those around them. Moreover, feelings of hatred, boredom and irritability were replaced by love, appreciation and the pursuit of children's educational growth, movement and language development and upbringing. These mothers stated that by trusting in God and trusting in themselves, they were able to deal with and overcome this problem.

The results of the quantitative analysis confirm the results of the qualitative analysis. According to the mean values of the parents' emotional cognitive regulation, it is clear that parents with DS have higher values for positive cognitive regulation and lower values for negative cognitive regulation than parents with normal children. On other words, [34], acceptance in humans is a person's agreement with the reality of a situation. In everyday situations, acceptance can help us come to terms with both internal and external challenges, which can lead to greater resilience and emotional well-being. Acceptance contributes to effective coping with adversity, reduced stress, and improved emotional well-being.

# Acknowledgments

The authors would like to thank the Najaf Abad Mehr Center, Ms. Mokhtari, and the families of the DS children for their cooperation during the various stages of this study.

#### **Ethical Considerations**

This study was commenced after approval from the Institutional Ethics Committee (Ethical code: IR.YAZD.REC.1400.012).

#### **Funding**

There was no financial support for this research.

#### **Conflict of interest**

There is no conflict of interest.

# References

 Ramezanali S, Vaez Mousavi MK, Ghasemi A. Reliability of Static and Dynamic Balance Tests in

- People with Down Syndrome. J Disability Studi 2022; 12: 57.
- Teymouri R, Hemmati S, Teymouri F, Scientists N. Perceptual and production disorders in children with DS. 4th National Seminar on Children with DS in Tehran 2014; 31-32.
- Tarui T, Im K, Madan N, et al. Quantitative MRI analyses of regional brain growth in living fetuses with Down syndrome. Cerebral Cortex 2020; 30(1): 382-90.
- 4. National down syndrome society ndss 2019. https://www.ndss.org (Available at 20 Dec. 2023).
- Healthline.com/helth/down.syndrome#outlook 2017; https://www.Helthline.com (Available at 12 Jan. 2024).
- Van Cleve SN, Cohen WI. Part I: clinical practice guidelines for children with Down syndrome from birth to 12 years. J Pediatr Health Care 2006; 20(1): 47-54.
- Watson-Scales S, Kalmar B, Lana-Elola E, et al. Analysis of motor dysfunction in Down Syndrome reveals motor neuron degeneration. PLoS genetics 2018; 14(5): 1007383.
- 8. Rice FP. Human Development: Llife-span Approach 2011: 4th ed
- Mohammad Khan Kermanshahi S, Vanaki Z, Ahmadi F, Azad Fallah P, Kazemnejad A. Mothers' experiences of having a mentally retarded child. Rehabilitation Research Journal 2006; 7(3): 26-33.
- 10. Staneva A. Breaking the prenatal depression taboo 2015; https://www.elsevier.com
- 11. Hadizadeh T, Abbasi S, Eini Mir Koohi Z. The relationship between resilience and coping styles in mothers with DS children. 6th National Congress of Family Pathology, Family Research Institute, Shahid Beheshti University Tehran 2014; Available from: <a href="https://sid.ir/paper/880609/fa">https://sid.ir/paper/880609/fa</a> [Text in Persian].
- 12. Kargar M, Asghari Ebrahimabad M J. Comparison of problem solving style and marital adjustment in mothers of exceptional and normal children. Journal of Exceptional Education 2015; 13(2): 37-44.
- 13. Karami Nejad R, Afrooz G, Shokoohi-Yekta M, Ghobari Bonab B, Hasanzadeh S. Lived Experience of Parents of Infants with Down Syndrome from Early Diagnosis and Reactions to Child Disability. The Journal of Tolooebehdasht 2020; 19 (3):12-31

- 14. Kring AM, Sloan DM. Emotion Regulation and Psychopathology: A Transdiagnostic Approach to Etiology and Treatment. 1st ed. Guilford Press book 2009.
- Azadpur A, Mahmoodi G. Quality of life and coping mechanisms of parents Down's syndrome and normal. "M.A"Thesis. university Tehran 2012. https://elmnet.ir/doc/10578809-51771.
- 16. Al otabi M, Farouk Helmy F, Amin Alsulaimani A, Basiouny R. Depression among mothers of down syndrome children. World Journal of Pharmaceutical Research 2015; 4(9): 177-92. https://wjpr.s3.ap-south-1.amazonaws.com/article\_issue/1441000048.pdf.
- 17. Veek SM, C van der, Kraaij V, Garnefski N. Cognitive Coping Strategies and Stress in Parents of Children With DS: A Prospective Study. Intellectua and Developmental Disabilities 2009; 47(4): 295–306
- 18. Kafi F S, Javadian S R, Kalateh Sadati A. Living experience of mothers with autistic children. PhD Thesis. Islamic Azad University, Science and Research Branch of Tehran 2017
- 19. Irandak. Guide to research and researchers (work research) 2019; https://rah.irandoc.ac.ir/
- Garnefski N, Kraaij V. Cognitive emotion regulation questionnaire – development of a short 18-item version (CERQ-short). Personality and Individual Differences 2006; 41(6): 1045-53.
- 21. Samani S, Sadeghi L. The Adequacy of Psychometric Indices of the Cognitive Emotion Regulation Questionnaire. Journal of Psychological Models and Methods 2010; 1(1): 51-62
- 22. Besharat M. Cognitive Emotion Regulation Questionnaire: Instruction and Scoring (Persian Version). university Tehran, Journal of Developmental Psychology, Iranian Psychologists 2016; 13(50): 221-3
- 23. Jafarpour Mamghani S, Oskooi jam M, Hashemi T. Factor structure of Cognitive Emotion Regulation Questionnaire. Proceedings of the Sixth Congress of the Iranian Psychological Association. Contemporary Psychology 2017; Special Issue12: 471-67

- 24. Munezero M, Montero C S, Sutinen E, Pajunen J. Are They Different? Affect, Feeling, Emotion, Sentiment, and Opinion Detection in Text, researchgate.net 2014; 5(2): 101-11
- 25. Habibzadeh Z, Tavassoli A, Safiri K. Factors affecting parents' behavior with children with emphasis on gender. Master Thesis, Al-Zahra University - Faculty of Social and Economic Sciences 2013; https://irandoc.ac.ir/page/2685.
- 26. Khatib Shahidi M, Fatemi Ardestani F. Parental Preferences over Children's Sex:The Case Study of Iran. JPBUD 2018; 23(1): 29-57.
- 27. Naghdi N, Ghasemzadeh S, Ghobari Bonab B. Phenomenology of lived experiences of mothers of children with DS. Journal of Applied Psychological Research 2019; 10(2): 105-118
- 28. Skotko BG, Levine SP, Goldstein R. Having a son or daughter with Down syndrome: Perspectives from mothers and fathers. American Journal of Medical Genetics Part A 2011; 155(10): 2335-47.
- Fernández LS, Izuzquiza D. Percepciones parentales sobre el impacto del síndrome de Down en la familia 2017; 48(2).
- 30. Hemti S, Asadi AA, Mirspasi Z. Family burden and problems of people with Down syndrome. Archives of rehabilitation (rehabilitation) 2014; 6(3): 20-4.
- 31. Hemti S. How the nervous system develops in people with Down syndrome. Iran Down Syndrome Center 2018; DSCIran.com articles
- 32. Behnam B. Educational content and preparation of mentally retarded children in the field of independent life skills from the point of view of teachers and parents 2014; 5(3): 17.
- 33. Mohammadi P, Dadkhah A, Dolatshahi B, Hemti, S. Comparison of parenting practices and stress coping strategies of mothers of children with Down syndrome and controls. Master's thesis of the University of Welfare and Rehabilitation Sciences 2013.
- 34. Mrazek MD, Dow BR, Richelle J, et al. Aspects of acceptance: building a shared conceptual understanding. Front Psychol 2024; 15(1): 1423976.