

Research Paper

The Lived Experiences of the Mothers of Children With Speech Disabilities



Shourideh Seresht¹ , Anahita Khodabakhshi-Koolae^{2*} , Mohammad Reza Falsafinejad³

1. Department of Counseling, Faculty of Humanities and Social Sciences, Science and Research Branch, Islamic Azad University, Tehran, Iran.

2. Department of Psychology & Educational Sciences, Faculty of Humanities, Khatam University, Tehran, Iran.

3. Department of Assessment and Measurement, Faculty of Psychology and Educational Sciences, Allameh Tabataba'i University, Tehran, Iran.



Citation Seresht, S., Khodabakhshi-Koolae, A., Falsafinejad, M. R., 2022. The Lived Experiences of the Mothers of Children With Speech Disabilities. *Journal of Client-Centered Nursing Care*, 8(3), pp. 209-222. <https://doi.org/10.32598/JCCNC.8.3.33.18>.

<https://doi.org/10.32598/JCCNC.8.3.33.18>

**Article info:**

Received: 23 Apr 2022

Accepted: 08 May 2022

Published: 01 Aug 2022

Keywords:

Disabled children,
Speech-Language Pathology,
Parent-child relations, Social
stigma, Qualitative research

ABSTRACT

Background: The mother, as the first and foremost person interacting with the child, suffers the most from the child's speech disability. This study aimed to explore the lived experiences of mothers of children with speech disabilities.

Methods: This qualitative study was conducted using a descriptive phenomenological approach and purposive sampling in Tehran, Iran in 2021. Data were generated through 20 semi-structured interviews with mothers whose children needed speech therapy for at least six months and had been referred to speech therapy centers in Tehran, Iran. The interviews continued until data saturation. Data analysis was performed using Colaizzi's seven-step method.

Results: Four main themes and nine subthemes emerged, including intrapersonal suffering (psychological pressure and physical pain), feeling empty (lack of husband support and lack of support from the husband's family), interpersonal conflicts (challenge with therapists and facing public reaction), and need for balance (self-imposed social exclusion/isolation, take refuge in superstitions out of despair, and take refuge in the support of peer mothers).

Conclusion: The results of this research revealed that paying attention to the inner suffering and pain experienced by these mothers is necessary. Support from their husbands and health workers could help them to better resolve the conflicts and create balance in their lives. Implementation of psychological interventions to reduce the subjective and objective burden of these mothers and involving them in counseling sessions can reduce their anxiety and stress.

*** Corresponding Author:**

Anahita Khodabakhshi-Koolae, PhD.

Address: Department of Psychology & Educational Sciences, Faculty of Humanities, Khatam University, Tehran, Iran.

Tel: +98 (21) 8917 4119

E-mail: a.khodabakhshid@khatam.ac.ir

Highlights

- The lived experiences of mothers of children with speech disorders can help mothers and healthcare professionals.
- Four main themes emerged from this phenomenological study were as follows: intrapersonal suffering, feeling empty, interpersonal conflicts, and the need for balance.
- In addition, the results indicated nine subthemes, including psychological pressure, physical pain, lack of husband support, lack of support from the husband's family, the challenge with the therapist, facing public reaction, self-imposed social exclusion/isolation, taking refuge in superstitions out of despair, and refuge in the support of peer mothers.

Plain Language Summary

Awareness of mothers' experiences of living with a child with a speech disorder will help healthcare professionals better understand their needs. In this study, four main themes emerged from the interviews, including intrapersonal suffering, feeling empty, interpersonal conflicts, and the need for balance.

1. Introduction

The development of speech and language skills is specific to humans and compared to other skills, indicates the growth and maturity of the brain. The development of perceptual language (the ability to comprehend speech) usually occurs faster than expressive language (the ability to communicate) (Longe, 2021). The mother is the most important teacher in the early years of a child's life. Language is learned by listening to others and practicing it (CDC, 2021). Speaking and communication skills enable children to interact with others and learn from formal classroom education and the environment around them (Child Development Institute, 2019). The ability to use speech requires skills and coordination of different parts of the brain, nerves, and body (head, mouth, neck, chest, and abdomen) (Eske, 2019).

Speech disability is characterized by the inability to produce or organize sounds (letters) and syllables or spoken words or the fluency of speech and, consequently, the inability to express sentences and communicate with others. Some speech disabilities are the result of a congenital, genetic, or traumatic disorder, and others are influenced by a primary cause, such as developmental and cognitive disabilities and syndromes, attention deficit hyperactivity disorder (ADHD), learning disabilities, hearing disability, autism spectrum disorder, brain injury, and mental/emotional disorders (ASHA, 2017; Sanger et al. 2004). Speech and language disorders can be due to the defects in comprehension or production of any of the five areas of language, namely phonology (word recognition), morphology (word formation),

syntax (sentence construction), semantics (meaning of words and sentences), and pragmatics (social aspect and use of words in the right context). In addition, pediatric or developmental speech sound disorder (SSD) is a general term that includes a variety of diagnostic titles, such as speech delay, phonetic articulation disorder, consistent or inconsistent phonological disorder, and pediatric motor speech disorders with subtypes of childhood apraxia of speech and developmental dysarthria (Terband et al., 2014).

Language disorders may persist throughout life and their symptoms change over time (Sanger et al., 2004). Social communication disorders occur as a result of problems in the social use of verbal and non-verbal communication. For example, a person may have difficulty using words in the right social context, understanding situations to express feelings and ideas, and even starting and continuing conversations, etc. (Banjee et al., 2013). It has been shown that approximately 7.7% of 3-17-year-old children in the United States have a disorder related to voice, speech, language, or swallowing and 34% of them have multiple communication or swallowing disorders between the ages of 3 and 10 (national institute of deafness and other communication disorders (NIDCD), 2016). These disorders may have short- or long-term effects on health and cause learning problems in children (Hassanzadeh, 2020). Untreated speech-language problems lead to behavioral challenges, mental health problems, reading difficulties, poor academic performance, and high school dropouts (Prelock et al., 2008).

The most painful issue for mothers of children with speech and language disorders is that they face other challenges besides helping and exercising to improve their child's speech (ASHA, 2021). The birth of a child with a disability can lead the family to a psychological and emotional breakdown. Blame, guilt, depression, and inefficiency are some of the negative emotions experienced by mothers of children with disabilities. Thus, mothers as primary caregivers are exposed to more psychological stressors (Khodabakhshi-Koolaei, Koshki, & Kalhor, 2019; Rezaei et al., 2020). Compared to mothers of typical development children, they are unaware of their physical and mental health and suffer from isolation and apathy to establish relationships with others, which results in depression and endangering their mental health (Koolaei et al., 2014).

Mothers of children with speech and language disorders have difficulty understanding their child's needs as well as making the child understand what they want. When children are unable to express their needs, they often resort to loud crying or screaming. Moreover, the child's failure to understand the mother's expectations and advice due to comprehension problems causes anxiety and confusion for the mother, and as a result, disrupt the social relations of the family. Most of the time, the child's inability to express intelligible words leads to the use of pseudo-words and self-made words, which are only understood by the child and sometimes (but not often) by the mother. Thus, the mother must always be available to translate the needs of her child. Communication problems caused by speech and language disorders and their causes are often questioned by people around and the community members accompanied by popular advice (Khodabakhshi-Koolaei et al., 2019; Nur, Tairas, & Hendriani, 2018). Thus, the explanation by the mother causes irreparable harm to her. Finding the right treatment and intervention path, trusting the therapist, and going to rehabilitation centers are some of the other difficulties and problems experienced by these mothers. The first author of this article, during her 15 years of speech therapy experience for children with speech disorders and counseling with their mothers, has always witnessed the challenges of these mothers in the counseling sessions due to their child's disability.

So far, a few qualitative studies have been conducted on mothers of children with speech-language disorders (Nur et al., 2018; Macharey & Von Sachdoletz, 2008; Miron, 2012; Denmon, 2019). These studies have mainly focused on how parents understand speech-language disorders or have addressed the parents' communication with and expectations from the therapist and the type of

interventions. The lived experiences of Iranian mothers of living with a child with speech-language disorder not only lead to the development of a body of knowledge regarding this important issue but can also help rehabilitation intervention and counseling techniques for these children and mothers and the improvement of their mental and physical health, and could be helpful for mothers who have just been confused by taking this difficult path. Therefore, these mothers understand that their feelings and reactions are not specific to them but are universal. The aim of this study was to explore the lived experiences of mothers of children with speech disabilities. The results of this study can increase public awareness of the conditions of mothers of children with speech disabilities.

2. Materials and Methods

This qualitative study used a descriptive phenomenological approach and was conducted from April to September 2021. A qualitative phenomenological approach focuses as much as possible on the participants' first-hand experiences and tries to reveal the meanings and experiences of the individual as he/she has lived them. The descriptive phenomenological approach is used when there is little information about a subject and the aim is to study, clarify, and understand the most basic meaning of a phenomenon of interest from the perspective of those directly involved (Giorgi, 1997).

The participants in this study were mothers of children (3-9 years old) who had speech disabilities and as a result, had difficulty communicating normally according to their age. These mothers had referred to one of the four speech therapy centers in districts one or two of Tehran and their children were being treated in person or online by a speech and language pathologist. The informants were selected using purposeful sampling. Data generation continued until the data were saturated through interviews with 20 informants.

Inclusion criteria were having at least a high school diploma, not being treated by a psychiatrist, not having an acute physical illness, and voluntary cooperation in the study. The children have been receiving speech therapy for the past six months, their speech problems were in the range of pediatric or developmental speech sound disorder (SSD) as shown in Table 1, the age range of children was between three and nine years, and they had no hearing disability or hearing loss.

Maximum variation sampling was met through the selection of mothers in different age groups, diverse social and economic statuses, different education and marital status, and also gender diversity of their children. The data were generated through semi-structured interviews focusing on the experiences of mothers of children with speech disabilities. Each interview lasted approximately 60 minutes. Before the interviews, some information was provided to the participants about the study, its objectives, and the research procedure. Then, the participant's demographic characteristics were recorded (Table 1). Some of the questions asked in the interviews are as follows: "What was your reaction to your child's speech impediment?", "What was your feeling after learning about your child's speech disorder?", "What was the reaction of people and those around you to your child's speech disability?", "Which experiences have you had so far due to your child's speech disability?"

Subsequent questions were asked based on the informants' answers. The researcher valued the participants' silence (epistemological silence) so that they could recall their experiences well and come up with in-depth answers. The researcher also tried to motivate the participants by asking exploratory questions to express their understanding of lived experiences. For example, the following questions were asked: "Would you please explain more?", "Could you give me an example?" and "Did I get it right? "You meant that ...?"

Since this study was conducted during the COVID-19 outbreak, all the interviews were conducted by the researcher herself in-person and following health protocols in a private speech therapy center. For the participants' convenience, the interviews were conducted upon an appointment with them. However, subsequent follow-ups were performed by telephone. To better respond to the questions, the participants were given free time during the interviews to express what they have experienced and felt, and what they wanted to share with others. Therefore, some interviews lasted up to 3 hours and all interviews lasted 1620 minutes. The interviews were recorded with the informants' permission. The content of the interviews was then transcribed word by word, and data analysis was performed simultaneously.

Data analysis was performed following Colaizzi's seven-step method (Colaizzi, 1978). First, all the descriptions provided by the participants were written word by word immediately at the end of each interview and were read several times to understand the participants' feelings and experiences. In the second step, significant relevant non-repetitive statements were extracted.

The significant information and sentences related to the phenomenon in question were underlined and thus, the significant statements were identified. In the third step, code extraction, the related themes were extracted from the significant statements in each interview. To this end, a theme was extracted from each statement that showed the main idea behind the participant's statements. Furthermore, the relevance of the themes with the significant statements was checked. The researcher attempted to stay off her presuppositions and to be closer to the phenomenon as it has been experienced. In the fourth step, the identified concepts were classified into thematic clusters based on their similarities. In the fifth step, the thematic clusters were merged into broader categories to present a description of the phenomenon under study. In the sixth step, a thorough description of the phenomenon in question was provided. In addition, the researcher summarized the comprehensive description so that only the aspects that are considered necessary for the structure of the phenomenon are revealed. Finally, in the seventh step, the findings were reviewed and confirmed by the participants using follow-up phone calls.

To ensure the rigor of the study, the trustworthiness criteria proposed by Lincoln and Guba were used (Lincoln & Guba, 1985). To confirm credibility, prolonged engagement, member checks, and peer debriefing were used. To establish dependability, an inquiry audit was used so that the coding and analysis were controlled by the supervisor and co-supervisor of the study. Transferability was met through the thick description of the context of the study. Confirmability was established through the audit trail and external auditors agreed with the researchers' interpretations.

3. Results

Table 1 presents the participants' demographic data. The lived experiences of the participants emerged as four main themes and nine subthemes (Table 2).

Intrapersonal suffering

These mothers suffered a lot from their children with language and speech problems. This suffering had psychological, physical, and emotional dimensions and led to a decrease in their tolerance. This main theme consisted of two subthemes, including psychological pressure and physical pain.

Psychological pressure

The psychological pressure was constituted of initial categories, such as denial and shock, feeling sad, anger, bargaining with God, feelings of guilt and self-blame, feeling confused and perplexed, and constant worry about the child's uncertain future. The followings are some excerpts of the participants' experiences:

Denial and shock: Denial and shock emerged as not accepting the reality after hearing, seeing, or knowing about the unfortunate event. All the mothers stated that they were severely denying their child's disability after knowing about it: *"Like any other mother, I was expecting to have a healthy baby. Then something terrible happens like this! It was so horrible and painful; it was unbelievable to me at first. At first, I wanted to deny it. No! My son! It's impossible. I said to myself, no, he has no symptoms"* (Participant #3).

Feeling sad: The participants stated that they were unhappy with their child's problem: *"When my son still could not speak well; if I took him to a place where other children spoke, I would feel envious. I said to myself, oh, why should my child be like this! Many people in my family had children of the same age as my son. [Why didn't their children have the same problem?]"* (Participant #1).

Anger: Many mothers reported that they were experiencing severe anger after knowing about their children's problem. *"I was angry with myself when I compared my child to other children. I was very upset when someone asked me about it. I preferred to hide my anger. I tried to calmly explain to them and tell them what the problem was or why it happened. But I was very angry and upset inside"* (Participant #1).

Bargaining with God: The participants reported that they often thought they had been wronged by God: *"I was very angry. In fact, I was complaining about God"* (Participant #13). Another participant said, *"Every day I said blasphemy to the heaven. I was cursing God because I believed a lot in God I was saying, oh, God, why me? I begged God that if this child gets well, I will help the needy a lot"* (Participant #16).

Feelings of guilt and self-blame: Some participants reported that they felt guilty when they were alone and thinking about their child's disability: *"I blamed myself all the time and thought maybe I did something during my pregnancy. At the seventh month of both of my pregnancies, my body was always itching. I had liver cholestasis, I had to take pills, I said maybe my child's*

problem was because of the side effect of the pills I had taken" (Participant #5).

Feelings of confusion and perplexity: The women participating in this study reported that they often felt confused for a long time after becoming aware of their child's problem: *"Certainly, it was a very strange feeling that I do not know how to tell you, like a parent ..., a mother who loses her child! The loss of a child is a feeling of sadness that is not forgotten but eventually fades away, but unfortunately, when your child has a disability, you see it 24 hours a day"* (Participant #5).

Constant worry about the child's uncertain future: The participants stated that they were worried about the uncertainty of their child's future: *"What should he do when we are no longer living with him? I cannot count on his brother very much. He is a boy; we must put ourselves in girls' shoes. If I had a daughter, would I really like to marry a boy whose brother has a disability? Does her husband always want to take care of his brother?! So I cannot ask her to look after her brother. I just always wanted her to love and understand her brother"* (Participant #11).

Physical pain

Physical pain included three initial categories, including body aches and numbness, muscle stiffness, and neck stiffness. The followings are examples of the participants' experiences:

Body aches and numbness: Some of the participants reported feeling severe physical pain: *"I had physical pain and was suffering from severe back pain. I have been doing exercise for almost a year, thank God I have no problem now. But before, I was feeling as if my body was numb. I had pain in my hands and feet. I was suffering from pressure either physically or mentally"* (Participant #12).

Muscle stiffness: The mothers stated that they have experienced muscle pain during this period: *"My neck was stiff for a whole week. I searched the internet and found that I had signs of a stroke. I mean, I was under so much pressure. My stiffness was over with a few injections. But I resisted the problems and said it would finally fix"* (Participant #18).

Neck stiffness: Some participants reported that they recently have experienced headaches: *"I was shocked all at once. I was always having migraine headaches. My neck was very stiff. I felt faintness in my whole body"* (Participant #19).

Table 1. Participants' demographic data

Code	Age (y)	Education	Occupation	Marital Status	Number of Children	Birth Order	Child's Gender	Child's Age (y)	Economic Status	Language/Speech Disorder
1	49	Diploma	Employed	Married	1	First	Male	7	Good	Dysarthria
2	36	Bachelor's degree	Housewife	Married	1	First	Female	6	Good	Developmental speech and language delay
3	42	Bachelor's degree	Housewife	Divorced	1	First	Male	6	Very good	Developmental speech and language delay
4	29	Diploma	Housewife	Married	2	First	Male	9	Good	Dysarthria
5	40	Master's degree	Housewife	Married	2	Second	Female	3.5	Good	Developmental speech and language delay
6	38	Bachelor's degree	Housewife	Married	2	First	Male	6	Good	Developmental speech and language delay
7	51	Diploma	Housewife	Married	3	Second	Male	5	Moderate	Language and speech developmental delay
8	44	Diploma	Housewife	Married	1	First	Male	6	Good	Speech sound disorder
9	45	Master's degree	Housewife	Married	2	First	Male	9	Good	Developmental speech and language delay
10	39	Bachelor's degree	Employed	Married	2	Second	Male	8	Moderate	Stuttering
11	45	Diploma	Employed	Married	2	Second	Male	6	Good	Developmental speech and language delay
12	43	Bachelor's degree	Housewife	Married	2	Second	Male	5	Good	Developmental speech and language delay
13	43	Diploma	Housewife	Married	2	Second	Male	4	Good	Dysarthria
14	48	Master's degree	Housewife	Divorced	1	First	Male	6	Moderate	Dysarthria
15	45	Bachelor's degree	Employed	Divorced	2	First	Male	8	Moderate	Dysarthria
16	35	Bachelor's degree	Housewife	Married	3	Third	Female	3	Good	Developmental speech and language delay
17	34	Diploma	Self-employed	Married	1	First	Male	7	Moderate	Stuttering
18	34	Master's degree	Housewife	Married	3	Second	Female	7.5	Poor	Developmental speech and language delay
19	40	Diploma	Housewife	Married	2	First	Female	8	Good	Developmental speech and language delay
20	31	Diploma	Housewife	Married	1	First	Female	6	Good	Developmental speech and language delay

Table 2. The themes and subthemes emerged in the study

Main Themes	Subthemes	Initial Categories		
Intrapersonal suffering	Psychological pressure	Denial and shock		
		Feeling sad		
		Anger		
		Bargaining with God		
		Feelings of guilt and self-blame		
		Feeling confused and perplexed		
		Constant worry about the child's uncertain future		
		Body aches and numbness		
		Physical pain		
		Muscle stiffness		
Feeling empty	Lack of husband support	Neck stiffness		
		Feeling lonely		
		Opposition to parent participation in self-help groups		
		Verbal and emotional blame of the husband		
		Communication problems with the husband		
		Rejection of responsibility by the husband		
		Non-payment of medical expenses		
		The absence and escape of the husband		
		Lack of support from the husband's family	Psychological and social pressures from the husband's family	
			Attributing the disability to the genetic deficiencies of the mother and her family	
Interpersonal conflicts	Facing public reaction	Negative public reaction to disability		
		Asking frequent questions about child disorder		
		Preventing the mother from attending the treatment sessions		
		Failure to inform the mother of the child's disorder		
		Challenge with therapists	Not explaining treatment instructions	
			Failure to inform the mother about the course of the disease	
			Creating unrealistic treatment expectations and hopes in the mother	
		Need for balance	Self-imposed social exclusion/isolation	Evading social interactions with family and friends
				Refusing to talk to others
			Refuge in superstitions out of despair	Turning to fortune-tellers, sorcerers, and goblins
Feeding the pigeon eggs to the child*				
Refuge in the support of peer mothers	Interacting with mothers with the same problems			
	Participating in self-help groups			

Client-Centered Nursing Care

*There is an old misbelief in Iran whereby feeding pigeon eggs to a child with speech disorders helps the child speaks fluently (authors).

Feeling empty

The participants often lacked the support of their husbands and families and therefore, felt empty. This lack of support fueled their anxiety and loneliness. This main theme consisted of two subthemes, including lack of support from the husband and lack of support from the husband's family.

Lack of husband support

This subtheme consisted of initial categories, including feeling lonely, opposition to parent, verbal and emotional blame of the husband, communication problems with the husband, rejection of responsibility by the husband, non-payment of medical expenses, and the absence and escape of the husband. The following are excerpts of the participants' interviews:

Feeling lonely: The participants stated that they were alone because of their child's problems and felt they have no one: *"My husband once said on Friday that I would go to see a house after work. I was alone from morning till night. When he came home, I found that he was smoking hookah. I asked where he was. He told the story. I told him I had been alone at home since the morning until about 9 o'clock. I blamed him for not being fair enough not to leave his wife alone at home with her sick child for a long time"* (Participant #13).

Opposition to parent participation in self-help groups: One of the participants stated, *"Other mothers did a great job. They formed a group with 4 or 5 members. They held parties. They also joined a group in Telegram and shared their experiences and their routine works. They used to attend a party held at one of the members' houses once a week or a month. I think this would help them reduce their anxiety and stress a lot. Their husbands also attended the party. But I was very anxious because of my son and my husband. Because my husband had come to the association several times, he had argued with me. Almost everyone there was aware of our arguments"* (Participant #3).

Verbal and emotional blame of the husband: One of the participants stated *"I have been living apart from my husband for three years now. But he used to tell me that you were a nurse, your children should not have developed this problem. Look how short-sighted he is. These things may happen to anyone. He was looking for someone to blame her"* (Participant #15).

Communication problems with the husband: *"My husband rarely talks to me. Later, I found that our life was turning in a way that my husband's father did not like to visit us. We were alone in the house most of the time"* (Participant #1).

Rejection of responsibility by the husband: *"There were some arguments between us only because of my daughter's problem or that I was sick for three days when I was in the rehabilitation center. I did not tell my husband many things that day because he had a long way to go by car and I did not want to worry him anymore because we had a lot of financial problems"* (Participant #2).

Non-payment of medical expenses: *"Before we got separated, my brother gave me his credit card and told me to pay the costs of my child's speech therapy. I told my husband about it. Although I knew he would not be offended by it at all"* (Participant #3).

The absence and escape of the husband: *"My husband's reaction to the news of our child's disability was very bad. He had taken all her belongings and had gone away. We did not know about him for two days"* (Participant #4).

Lack of support from the husband's family

The husbands' families often not only had not supported these mothers but also contributed to their suffering. This subtheme consisted of the initial categories, including psychological and social pressures from the husband's family and attributing the child's disability to the genetic deficiencies of the mother and her family.

Psychological and social pressures from the husband's family: *"Earlier, my mother-in-law said it was my fault that I did not play with the child or I would not talk to her. But I love my children very much"* (Participant #7).

Attributing the child's disability to the genetic deficiencies of the mother and her family: *"One day a member of my husband's family asked why you did not have an abortion? I could not explain the speech disorder to them because they were not educated. When my husband's mother saw our child, she said that the cousin of my aunt's mom has six fingers so the child's disability was caused due to genetic problems inherited from my family members"* (Participant #2).

Interpersonal conflicts

The child's speech problems had caused a lot of problems for the mothers because they had to constantly explain it to people or face their bad reactions. In addition, therapists often had not paid attention to the needs of these mothers, which led to a doubling in their suffering. This main theme consists of two subthemes, including facing public reaction and challenges with therapists. Some excerpts from interviews with mothers are as follows:

Facing public reaction

Negative public reaction to disability: *"Public awareness about disabilities is very low. When I first went to the small city where I live, many people pointed to the cochlear implant and asked what it was and what was its purpose and functions. They admitted that they had not seen it before. They thought that the child had a brain problem as they saw a curled thing within her ear"* (Participant #20).

Asking frequent questions about child disorder: *"There are many people who ask about my child's problem and its causes. They made us angry because they wanted to know why our daughter could not speak and why she has started speaking so late. People asked why she speaks in that way and advised us to take her to a speech therapy center, as if they were more sympathetic than us as her parents"* (Participant #6).

Challenge with therapists

Although therapists had helped children improve their speech, they had behaviors that had led to mothers being upset and stressed. This subtheme consisted of five initial categories, including preventing the mother from attending the treatment sessions, failure to inform the mother of the child's disorder, not explaining treatment instructions, failure to inform the mother about the course of the disease, and creating unrealistic treatment expectations and hopes in the mother.

Preventing the mother from attending the treatment sessions: *"During the therapy sessions, they did not allow me to be with my daughter. Then I protested and said that her father had insisted that I had to be with her in the session. They allowed me to attend the session and I saw that they were harassing her"* (Participants #4).

Failure to inform the mother of the child's disorder: The participants stated that the therapist did not provide any information about the child's disorders and this made them more anxious: *"I did not know from the beginning that this is a permanent problem and nobody told me. Maybe they did not want to say it! They did not say that this problem may last for years or even would be with the child for the rest of his life!"* (Participant #1).

Not explaining treatment instructions: *"Let me tell you a memory from the first speech therapy. I took my son to speech therapy for two sessions. A woman was supposed to come home to do speech therapy with him. The woman asked me not to give him anything even food when he's hungry until he asks for it and he is forced to speak. Thus, I kept the child hungry one morning until the afternoon to force him to say that he is hungry but he couldn't do it. When I still think about him, I get very upset. I say to myself, I wish I had not done this to my child. He could not speak!"* (Participant #1).

Failure to inform the mother about the course of the disease: *"It was very terrible because at first I was given wrong information. My daughter was small and they told me that she has no speech problem, but later I found that she knew and spoke fewer words than those used by other children of her age. I took her to a speech therapy center and they told me that her muscles were weak and she needed to undergo the treatment"* (Participant #2).

Creating unrealistic expectations and hopes for treatment in the mother: *"The therapists have to tell me everything from the beginning. For example, they needed to tell me that my child's problem is permanent and do not give me false hope. I think they shouldn't do that"* (Participant #2).

Need for balance

The experiences of the mothers of these children showed their need to balance life; thus, they tried to stay away from others or resort to anything to relax a bit. This main theme consisted of subthemes, including self-imposed social exclusion/isolation, a refuge in superstitions out of despair, and refuge in the support of peer mothers.

Self-imposed social exclusion/isolation

One way to balance life was to withdraw from others, which was in the form of evading social interactions with family and friends and refusing to talk to others.

Evading social interactions with family and friends:

The participants stated that they were reluctant to communicate with others for fear of being judged: *“I barely had any communication with my family and my husband’s family. Even I had less relationship with my husband. Whenever we were together, we used to talk only about our child”* (Participant #1).

Refusing to talk to others: The participants reported that they needed to talk but to someone who does not judge them: *“I was very lonely. I believe that I should not involve other people in my own affairs and do not disturb them. Thus, I did not talk to anyone. I had nothing to say to my poor mom. I used to hide my problems. I felt I was very lonely. There was nobody to listen to me so that I could relieve myself from grieves. There was nobody so that I could talk to him/her without later feeling that he/she was feeling unhappy because of me”* (Participant #2).

Refuge in superstitions out of despair

The mothers had done everything they could to cure their children, often resorting to the supernatural out of necessity. This subtheme consists of initial categories, including turning into fortune-tellers, sorcerers, and goblins, and feeding the pigeon eggs to the child.

Turning to fortune-tellers, sorcerers, and goblins: *“I even tried fortune-teller. Even there was a person who came to our house every Thursday. He worked with stones. She said the child was hurt badly by an evil eye. Suppose 17 years ago, when my son was 3 years old, I gave 3 million Tomans (Iranian money) to a sorcerer. She placed my son on a chair with rose water and green cloth and charred all over his body. She wrote some magical words on a piece of paper and claimed that she pulled the jinn out of his body”* (Participant #11).

Feeding the pigeon eggs to the child: *“My mother brought some pigeon eggs and said that feeding pigeon eggs to the child cures him. I told her that the child stutters and this problem would be solved, but you know, my mother does such things out of compassion”* (Participant #17).

Refuge in the support of peer mothers

The experiences of these mothers indicated the need to associate with people who had a similar problem. Therefore, they felt that they were not alone. This subtheme had the initial categories, including interacting

with mothers with the same problem and participating in self-help groups.

Interacting with mothers with the same problem:

“There are several pages on Instagram whose followers are the mothers of children with speech disabilities. They share very nice things. Seeing them boosts my self-confidence. It seems that a child’s disorder is a small issue that does not need to be hidden! When I see these things, I try not to hide my child’s disability and encourage myself to interact with other people” (Participant #16).

Participating in self-help groups: *“I had a lot of contact with mothers of children with speech disabilities. Especially when I came to the rehabilitation clinic; I asked them a lot of questions, which calmed me down”* (Participant #6).

4. Discussion

The mothers’ experiences emerged in four main themes, including intrapersonal suffering, feeling empty, interpersonal conflicts, and the need for balance. The experiences of the mothers of children with speech disabilities showed many psychological negative reactions because they were worried about the future of their children. Similarly, Khodabakhshi-Koolae et al. examined the challenges faced by mothers in caring for their disabled children and concluded that mothers have experienced severe negative reactions and feelings and found themselves helpless and disappointed. Moreover, the mothers’ worries about their child’s future greatly disturbed them (Khodabakhshi-Koolae et al. 2019).

Mothers of children with speech disabilities endure many objective and subjective burdens along with feelings of loneliness or isolation and also a sense of losing friends, relatives, life, and social position (Koolae et al. 2014). The results of the present study showed that mothers used to resort to superstitions out of desperation. People resort to superstitions in critical situations characterized by fear and hope and in moments when there is uncertainty about the future, leading to confusion and skepticism. However, belief in mystical forces and superstitions has a long history in human societies. However, such belief does not exist in medical treatments (Kyriakides, 2016). People under psychological and social pressures caused by stigmas rely on superstitions and superstitious behaviors (Jahanshahi Afshar, 2014). For some people, superstitious and mystical beliefs prevent the medical cure and healing process. Therefore, they will refer to medical care, when all superstitions and fortune-teller attempts have failed (Jegade, 2002).

These mothers also reported “extreme unhappiness”, “anger”, “loneliness”, “guilt and shame”, “confusion, and “severe physical pain and suffering”. These findings were also reported by other authors (Barbosa et al., 2008). Feelings of sadness, grief, loneliness, and anger seem to be the result of pity or misunderstanding by people, the child’s disability, or the result of irrational beliefs and fear of rejection. Feeling lonely is an objective phenomenon whereby a person experiences emptiness, sadness, and apathy, and can have negative effects on the person’s lifestyle and health (Ellis et al., 2019; Macharey, & Von Suchodoletz, 2008; Auert et al., 2012). Furthermore, excessive worries resulting from fatigue, loneliness, anxiety, frequent cognitive errors, and excessive workload (going to medical centers, doing homework, etc.) lead to mothers’ confusion. Unfortunately, excessive stress, physical problems, and pain in the mother are associated with a decrease in her tolerance threshold, which sometimes leads to intolerance of the child’s actions or his/her punishment (Khodabakhshi-Koolaee et al., 2019; Ellis et al., 2019).

The mothers of children with speech disabilities also complained about public reactions including public negative reactions to the child’s disability and frequent questions asked by people about the child’s disorder. This finding was consistent with the results reported by Marcheti Barbosa et al. (2008) and Khodabakhshi-Koolaee et al. (2019).

Given the lack of public awareness of children’s disabilities, some Iranian people have failed to develop a mature and rational view of language and speech disorders and disabilities, as if the participants in this study stated that they had not had any information about speech inabilities until their child became involved in such disabilities. In such cases, people are more likely to stigmatize children. Stigmatization by the public has been reported by the parents of children with developmental disorders (Nur et al., 2018).

The findings revealed that the mothers lacked the support of their husbands and their families. It has been shown that changes in family relationships and parents’ estrangement occur after awareness of speech disorders in children (Barbosa et al., 2008). It can be concluded that the fathers are shocked from hearing about the problem of their child and perhaps, they often prefer to run away from the problem instead of facing it. First, by denying the disorder, and less engagement, and then blaming the mother and her genetic problems, they try to get rid of the pressure and responsibility for this difficult and exhausting situation. Some avoid paying for treatment

costs and do not consider speech therapy effective. Thus, the mother is not allowed to continue treatment and communicate with other mothers.

One of the unpleasant experiences of most mothers was the therapists’ failure to inform them about psychotherapy and therapeutic errors. In such a situation, some profiteers are aware of the mothers’ desperation and seek to increase their income with false promises. While the process of treating language and speech disorders requires time and practice at home. It has been shown that for a person to recover faster, speech therapists should prioritize treatment over their own income and the parents should also be aware of the intervention process (Auert et al., 2012). The development of a trusting parental relationship with speech and language pathologists and attending therapy sessions for better functioning have been emphasized. Informing the mother about the type of language disorder, available treatment methods, the child’s progress, having honesty, and letting them participate in the therapy sessions are very effective in the treatment process (Melvin, Meyer, & Scarinci, 2020). Unfortunately, in some Iranian people, often materialist view prevailed and they think that medical advice is often for more money. Having real hope is very helpful for mothers whose children have language delays and realistic hope can be more effective in the treatment of their children (Nur et al., 2018). Parents of children with speech disabilities have a much lower quality of life compared to mothers with healthy children and low quality of life can negatively affect all aspects of their lives (Aras et al., 2014). Therefore, having health literacy and knowledge on how to help a child with a disability can lead to a better quality of life for mothers and a better parent-child relationship (Khodabakhshi-Koolaee et al., 2018).

In general, the degree of adaptation of mothers to their sick children depends on their psychological conditions, level of education, and also economic and social status (Miron et al., 2012). Moreover, Denmon showed that parents of children with speech disabilities endure a lot of stress and psychological pressures; therefore, joining support groups that can provide psychological and therapeutic services online to parents and their children can be very useful (Denmon, 2019).

One of the main problems of the mothers was the lack of proper communication between them and medical staff, especially, language disorder professionals. Mothers had not given an explanation about the treatment process; thus, their expectations of their children being treated were unrealistic. In future research, it is recommended to study the experiences of these mothers in dealing with lan-

guage disorder therapists and their problems. Most mothers and their husbands disagreed on the cost, attendance in therapy sessions, and effectiveness of speech therapy, and fathers were not willing to cooperate with mothers. In future research, the study of experiences and psychological reactions of fathers from having children with speech disabilities is suggested. Implementation of psychological and psychiatric interventions to reduce the subjective and objective burden of these mothers seems necessary. This study had some limitations. First, this qualitative research was based on the lived experiences of participants who had grown up in a specific cultural and social context (Iranian society). Second, this study was conducted in speech therapy centers in Tehran; thus, its findings, in general, do not reflect the mothers' lived experiences and psychological reactions of the entire population of mothers of children with speech disabilities.

5. Conclusion

Having a child with a speech impediment puts a lot of stress and a burden of care on mothers. The aim of this study was to explore the lived experience of mothers of children with speech disorders. The findings indicated four main themes, including intrapersonal suffering, feeling empty, interpersonal conflicts, and the need for balance. The results of this research revealed that paying attention to the inner suffering and pain experienced by these mothers is necessary. Support from their husbands and their family will create a sense of support in them. Increasing public awareness and understanding of these mothers by speech disorders specialists can reduce interpersonal conflicts. Also, these women need to balance their lives in a positive and logical way, and therefore, it is necessary to give them the necessary knowledge in this regard. Implementation of psychological and psychiatric interventions to reduce the subjective and objective burden on mothers seems necessary. Thus, educating and informing mothers and involving them in counseling sessions can reduce their anxiety and stress in mother-child interaction.

Ethical Considerations

Compliance with ethical guidelines

The article was registered in the Iran National Committee for Ethics in Biomedical Research (IR.IAU.SRB.REC.1400.120). To comply with the ethical principles of voluntary participation, written informed consent was obtained from the participants for conducting and recording the interviews. The participants were also reassured of the confidentiality of their information.

Funding

This article was extracted from the MSc. thesis of the first author, Department of Counseling, Faculty of Humanities and Social Sciences, [Science and Research Branch, Islamic Azad University, Tehran](#).

Authors' contributions

All authors equally contributed to preparing this article.

Conflict of interest

The authors declared no conflict of interest.

Acknowledgments

The authors would like to appreciate the officials in the speech therapy centers in Tehran, and the mothers who cooperated closely with them, as well as their children.

References

- Aras, I., et al. 2014. Health related quality of life in parents of children with speech and hearing impairment. *International journal of pediatric otorhinolaryngology*, 78(2), pp. 323-9. [DOI:10.1016/j.ijporl.2013.12.001] [PMID]
- ASHA, 2017. Spoken language disorders [Internet]. American, Speech-Language-Hearing Association. [Link]
- ASHA, 2021. How parents can help children with speech and language disorders in virtual and modified in-person classroom settings [Internet]. [Link]
- Auert, E. J., et al. 2012. Parents' expectations, awareness, and experiences of accessing evidence-based speech-language pathology services for their children with autism. *International Journal of Speech-Language Pathology*, 14(2), pp. 109-18. [DOI:10.3109/17549507.2011.652673] [PMID]
- Banajee, M. M., et al. 2013. Social communication disorder [Internet]. American Speech-Language-Hearing Association. [Link]
- Barbosa, M. A. M., Chaud, M. N., & Gomes, M. M. F., 2008. Experiences of mothers of disabled children: A phenomenological study. *Acta Paulista de Enfermagem*, 21(1), pp. 46-52. [DOI:10.1590/S0103-21002008000100007.]
- CDC. 2021. Developmental Disabilities. Child Development, Language Disorders. *Centers for Disease Control and Prevention*. [Link]
- Longe, J. L., 2021. The gale encyclopedia of children's health. Detroit: Gale, a Cengage Company. [Link]
- Child Development Institute, 2019. language development in children. LLC, 2230 W Chapman Ave, Suite 200, Orange, CA 92868, 800-283-2973. [Link]

- Colaizzi, P. F., 1978. Psychological research as the phenomenologist views it. Valle R. S., & King, M., editors. *Existential-phenomenological alternatives for psychology*. United Kingdom: Oxford University Press. [Link]
- Denmon, M. E., 2019. *Exploring an online support group devoted to parents of children with speech impairments: A qualitative multiple case study* [PhD, dissertation]. Mary Ellen Gross, Northcentral University. [Link]
- Ellis, R., et al. 2019. Reliability of one-repetition maximum performance in people with chronic heart failure. *Disability and Rehabilitation*, 41(14), pp. 1706-10. [DOI:10.1080/0963828.2018.1443160] [PMID]
- Eske, J., 2019. What are speech disorders? [Internet]. Medical News Today. [Link]
- Hassanzadeh, L., 2019. [Prevalence of speech disorders in children: A review study (Persian)]. Paper presented at the 12th university student conference on innovation in health sciences, Tehran, Iran, 1 May 2019. [Link]
- Jahanshahi Afshar, A., 2014. [The superstition origins and its function in people's life (the studied sample: Kerman people's beliefs) (Persian)]. *Culture and Folk Literature*, 2(3), pp.49-78. [Link]
- Jegade, A. S., 2002. The Yoruba cultural construction of health and illness. *Nordic Journal of African Studies*, 11(3), pp. 322-35. [Link]
- Giorgi, A., 1997. The theory, practice, and evaluation of the phenomenological method as a qualitative research procedure. *Journal of Phenomenological Psychology*, 28(2), pp. 235-60. [DOI:10.1163/156916297X00103]
- Kyriakides, T., 2016. Jeanne favret-Saada's minimal ontology: Belief and disbelief of mystical forces, perilous conditions, and the opacity of being. *Religion and Society*, 7(1), pp. 68-82. [DOI:10.3167/arrs.2016.070105]
- Ketelaars M. P., et al. 2011. Semantic abilities in children with pragmatic language impairment: The case of picture naming skills. *Journal of Speech, Language, and Hearing Research*, 54, pp. 87-98. [Link]
- Khodabakhshi-Koolae, A., Koshki, M. A., & Kalhor, N., 2019. [Analysis the experiences of mothers in caring of a disabled child: A phenomenological study (Persian)]. *Iranian Journal of Pediatric Nursing*, 6(2), pp. 68-75. [Link]
- Koolae, A. K., Baghersad, H., & Rahmatizadeh, M., 2014. The psychological effects of having a child with a speech disorder. *Middle East Journal of Psychiatry and Alzheimers*, 84(1262), pp. 1-6. [DOI:10.5742/MEJPA.2014.92514]
- Lincoln, Y. S., & Guba, E. G., 1985. *Naturalistic inquiry*. Newbury Park, CA: Sage Publications. [DOI:10.1016/0147-1767(85)90062-8]
- Macharey, G., & Von Suchodoletz, W., 2008. Perceived stigmatization of children with speech-language impairment and their parents. *Folia Phoniatrica et Logopaedica*, 60(5), pp. 256-63. [DOI:10.1159/000151763] [PMID]
- Melvin, K., Meyer, C., & Scarinci, N., 2020. What does "engagement" mean in early speech pathology intervention? A qualitative systematized review. *Disability and Rehabilitation*, 42(18), pp. 2665-78. [DOI:10.1080/09638288.2018.1563640] [PMID]
- Miron, C., 2012. The parent experience: When a child is diagnosed with childhood apraxia of speech. *Communication Disorders Quarterly*, 33(2), pp. 96-110. [DOI:10.1177/1525740110384131]
- NIDCD, 2016. Quick statistics about voice, speech, language [Internet]. National Institute on Deafness and Other Communication Disorders, Health info, Statistics and Epidemiology. [Link]
- Nur, H., Tairas, M. M. W., & Hendriani, W., 2018. The experience of hope for mothers with speech language delay children. *Journal of Educational, Health and Community Psychology*, 7(2), pp. 104-17. [DOI:10.12928/jehcp.v7i2.8936]
- Prelock, P. A., Hutchins, T., & Glascoe, F. P., 2008. Speech-language impairment: How to identify the most common and least diagnosed disability of childhood. *The Medscape Journal of Medicine*, 10(6), p.136. [Link]
- Rezaei, M., et al. 2020. Identifying the psychological challenges of mothers with a chronically ill child: A phenomenological study. *Journal of Qualitative Research in Health Sciences*, 9(1), pp. 18-27. [DOI:10.22062/JQR.2020.90999]
- Sanger, D., et al. 2004. Speech-language pathologists' opinions on communication disorders and violence. *Language, Speech, and Hearing Services in Schools*, 35(1), pp. 16-29. [Link]
- Terband, H., Van Brenk, F., & van Doornik-van der Zee, A., 2014. Auditory feedback perturbation in children with developmental speech sound disorders. *Journal of Communication Disorders*, 51, pp. 64-77. [DOI:10.1016/j.jcomdis.2014.06.009] [PMID]

This Page Intentionally Left Blank