

INTERNATIONAL JOURNAL
of
CONTEMPORARY
EDUCATIONAL RESEARCH

JCER

International Journal of Contemporary Educational Research (IJCER)

www.ijcer.net

Growing Up with an Additional Disabled Child: The Life Story of a Mother

Emrah Marul¹, Hasan Hüseyin Yıldırım²

¹Recep Tayyip Erdoğan University,  0000-0001-7084-3044

²Bolu Abant İzzet Baysal University,  0000-0001-5125-8069

Article History

Received: 29.02.2023

Received in revised form: 09.07.2023

Accepted: 10.08.2023

Article Type: Research Article



To cite this article:

Marul, E. & Yıldırım, H., H. (2023). Growing up with an additional disabled child: the life story of a mother. *International Journal of Contemporary Educational Research*, 10(3), 569-580. <https://doi.org/10.52380/ijcer.2023.10.3.423>

This article may be used for research, teaching, and private study purposes.

According to open access policy of our journal, all readers are permitted to read, download, copy, distribute, print, link and search our article with no charge.

Authors alone are responsible for the contents of their articles. The journal owns the copyright of the articles.

The publisher shall not be liable for any loss, actions, claims, proceedings, demand, or costs or damages whatsoever or howsoever caused arising directly or indirectly in connection with or arising out of the use of the research material.

Growing Up with an Additional Disabled Child: The Life Story of a Mother

Emrah Marul^{1*}, Hasan Hüseyin Yıldırım²

¹Recep Tayyip Erdoğan University

²Bolu Abant İzzet Baysal University

Abstract

The aim of this study, which was carried out according to the life story/narrative research design, which is one of the qualitative research methods, is to examine the life story of a mother living with a child with an additional disability. In this context, a 5-year-old child with deficiencies such as hearing loss, autism, and ADHD and his mother were included in the study. The research data consists of semi-structured interviews, observations, and document analysis. The collected data were analyzed with the inductive analysis method. As a result of the analysis, four main themes and ten sub-themes were identified. It was found that the mother had problems with the child's diagnosis, the use of hearing aids, placement in appropriate educational environments, familial support, and social support services. Based on these problems, suggestions have been made regarding legal arrangements and the planning of relevant legislation.

Keywords: additional disability, child, mother, life history, narrative research

Introduction

An estimated 40% of children with hearing loss have additional disorders that may affect education and adaptive development (Gallaudet Research Institute, 2003). These children should undergo comprehensive psychological evaluations for a variety of reasons. Additional disability is a term that describes the co-occurrence of two or more disabilities (Eldeniz-Çetin, 2013; Westling & Fox, 2009). Children with additional disabilities may have more needs in their developmental processes than their peers with one disability. They show significant limitations in terms of being able to live independently in their daily lives (Westling & Fox, 2009). These children, who constitute a homogeneous group compared to their peers, need more support (Bruce, 2011; Giangreco, 2006). Many children with additional disabilities, whose incidence or prevalence is low, continue their lives through home care services without being in school. All these disabilities seen in children can create some difficulties not only in the child's life but also in the family in which they live.

Previous studies have stated that families experience problems in their family order with the birth and participation of a child with a single disability and consequently experience a stressful parenting period (Clark & Drake, 1994; Davis & Carter, 2008; Seltzer et al., 2001). Especially the process starting with the birth of the child can lead parents to different emotional difficulties. These challenges include stress, financial and economic problems, spiritual difficulties, decreased quality of life, depression, and other emotional states that develop due to them (Farrel & Khan, 2014; Hallahan et al., 2018; İnce & Yıkılmış, 2021; Wake & Carew, 2016). Mothers frequently experience emotions such as guilt, anger, and not accepting the situation during these periods (Lederberg & Golbach, 2002; Zaidman-Zait, 2007). At first, it is known that a child with a disability negatively affects the daily activities of families (Barnett & Boyce, 1995) and the well-being of families (Gray & Holden, 1992). Among the family members who are most negatively affected by the process are mothers, who are usually the primary caregivers of children.

After the child's birth, the mother spends the most time during the developmental process (Hill, 2015; Karabulut & Tavit, 2016). The needs of a child with additional disabilities may be different and more complex than those of a child with typical development or a child with a disability. Meeting these needs can sometimes cause mothers to find themselves in an exhausting process (Nakken & Vlaskamp, 2007; Van Timmeren et al., 2016).

* Corresponding Author: *Hasan Hüseyin Yıldırım, hhyildirim96@gmail.com*

In studies on children with additional disabilities, it has been concluded that mothers spend more time caring for their children than mothers of typically developing children (Luijckx et al., 2017; Mencap, 2001; Tadema & Vlaskamp, 2010). It is very important to understand the experiences of mothers, who are the primary caregivers, during the process and to determine how they can solve these experiences or what the places are where they cannot solve them. Exploring this process will help improve the quality of the support services provided to mothers. At the same time, the mother will ensure improvements in the organization of policies and planning (Hill, 2015).

When the literature is examined, studies address the difficulties experienced by mothers with children with additional disabilities (Graungaard & Skov, 2007; Karadağ, 2009; Sardohan-Yıldırım & Akçamete, 2014; Sardohan-Yıldırım & Vezne, 2022) and the needs of families experiencing these difficulties (İnce et al., 2022; Redmond & Richardson, 2003; Sloper & Turner, 1992). There are also studies based on the opinions of families (Bahçivanoğlu-Yazıcı & Akçin, 2014; McIntyre et al., 2004). There is no study directly dealing with the life story of a mother who has a child with an additional disability. When evaluated in this context, this study constitutes the first example of a study in the national literature designed as life story or narrative research that tries to explore the process of a mother with a child with an additional disability from the birth of her child until the age of 5. Life story or narrative research allows us to collect information about people's lives and experiences. Thanks to this information, past knowledge and experiences can be transferred to the future. At the same time, it enables us to collect information about the process with individual life stories and, with this information, determine what solutions to offer to solve problems and what improvements to make.

Purpose of the Research

To understand the quality of education programs, support systems, and services offered in many areas for individuals with additional disabilities in Türkiye research on children with additional disabilities and their families should be conducted. Thanks to these studies, it is necessary to identify the negativities in the system and develop the necessary improvement and intervention systems. Through such research that tries to understand the other developmental stages of the child from the mother's life experiences, necessary arrangements can be made for children with additional disabilities and their families from the child's first diagnosis. For parents to accept their children with disabilities from the first moment and to establish a qualified interaction or relationship with them, studies on how the process works should be increased. This study aims to examine the life experience of the mother of a child with an additional disability from the birth of her child until the age of 5. Answers to the following research questions are sought for this purpose:

1. What are the mother's views on diagnosing the child with additional disabilities?
2. What are the mother's opinions about her life after learning that the child has an additional disability?
3. What are the mother's opinions about her experiences during the process?
4. What are the mother's opinions about her expectations and concerns about the child with additional disabilities?

Method

In this section of the study, information about the research design, the process of determining the participants of the research, the participants of the research, data collection techniques, data analysis, and the credibility of the research is presented.

Research Design

This study examines the mother's life experience with a child with autism spectrum disorder and communicative disability, in addition to hearing loss, from the birth of her child until the age of 5. Depending on this purpose, the research was conducted with a qualitative research method (Bogdan & Biklen, 1997). Qualitative research methods can be designed in different ways according to the subject and purpose of the study. Since this research examines the mother's life story of a child with an additional disability, it was designed as life story/narrative research (Creswell, 2012). In life story research, researchers pay attention to three important dimensions. These are: a) life has temporal dimensions and deals with temporal situations; b) focusing on individual experience and the social in a balanced manner by the research and its purpose; and c) occurring in specific places and in specific sequences (Clandinin & Connelly, 2000).

In life story research, we create field texts as we live in the field with our participants, whether it is a classroom, a hospital room, a meeting place where stories are told, or the participant's lived environment. Various field data collection techniques in life story research include photographs, field notes, interviews, and document analysis (Clandinin & Connelly, 2000). Life story research is defined as conveying the personal experiences of people who have lived the process to others from their perspectives (Ersoy & Bozkurt, 2017). Within the scope of this

study, the mother's experiences with her child with additional disabilities were examined based on her narratives.

Study Group

For the mother to be included in the study, qualifications such as having a child with an additional disability and having at least 3–5 years of experience with her child were sought. Within the scope of the research, forms containing brief information about the purpose, importance, and process of the research were shared with five special education and rehabilitation centers in two different cities. Then, the contact numbers of children with disabilities in addition to hearing loss and their families attending the rehabilitation centers were sent to the researcher with the permission of the families. The researcher conducted a preliminary interview with two families determined by the purpose of the study. After this interview, one of the families agreed to participate in the study. The necessary permissions for the research were obtained from the mother, who decided to participate in the study.

The participant's mother resides in a province in Türkiye. The mother, whose place of birth is different from her place of residence, is 35 years old. The mother graduated from high school and married at a very young age. The mother and her husband have been married for eight years and have two children. Both children are boys. The older child is 9 years old, attends the 4th grade of primary school, and has no disability.

The child with an additional disability was given the code name Emre. Emre is 4.5 years old and attends a special education and rehabilitation center. In addition, he attends a play therapy group and receives support training to improve his communicative skills. He goes to the rehabilitation center three days a week (Monday, Wednesday, and Friday). He attends the playgroup on Tuesdays. Emre has congenital hearing loss and was diagnosed through a newborn hearing screening. He underwent educational diagnosis and evaluation at the Guidance and Research Center and was diagnosed with autism spectrum disorder, attention deficit hyperactivity disorder, and hearing loss. Emre communicates intensively with signs. He can form single-word words. He has problems with social interaction and maintaining attention.

Data Collection Techniques

There are various data collection techniques in life story research, one of the qualitative research methods (Bogdan & Biklen, 1997). Within the scope of this research, semi-structured interviews were conducted according to the purpose of the study. Researchers diaries were written from the beginning to the end of the research. Observations were made to explore the natural environment of the mother and child at home. Documents related to the medical and educational background of the child were examined.

Interview

Interviews constitute life story research's primary data collection technique (Seggie & Bayyurt, 2015). Interviews with the participants include the process of getting in-depth information about their lives. This study conducted semi-structured interviews to examine the mother's life story in depth. According to the purpose of the study, interview questions were prepared after a detailed review of the literature. In the preparation of the questions, it was aimed at the mother to share the process of telling her life story. During the process, four different interviews were conducted with the mother. Each interview lasted an average of 54 minutes, and a total of nearly 5 hours of semi-structured interviews were conducted with the mother. Two of the interviews took place at the rehabilitation center where the child was attending, while the other two took place at the mother's home.

Diaries (Reflective Journal)

In the qualitative research method, researcher diaries are frequently used to understand the process of the research in detail and to find solutions to the problems encountered (Glesne, 2013). The researcher recorded diaries from the first stage of the research to the end. After each data collection process, the researcher recorded the diaries without spending too much time. During the research process, 70 minutes of researcher diary audio recordings were made.

Observations

The naturalness of the data collected through observations is ensured (Yıldırım & Şimşek, 2021). Within the scope of this study, permission was obtained in advance from the mother for observation at home. Then, video recordings were taken by entering their homes when they were available. The aim is to ensure that the child's additional disability is monitored and checked by another field expert. Five video recordings of the child's activities with his or her mother were taken. These videos were watched by another researcher who has expertise in the field of special education and additional disabilities, and his or her opinions about the child's additional disabilities were taken.

Document Review

To obtain supportive data from existing written or visual materials in the research process, document reviews are conducted in a qualitative research method (Yıldırım & Şimşek, 2021). The documents examined within the scope of this research consist of Emre's educational identification and evaluation forms, checklists containing the evaluations of his teachers at the rehabilitation center, and the result of the newborn hearing screening test.

Data Analysis

Within the scope of the current research, the data collected through interviews, researcher diaries, observations, and document reviews was analyzed and interpreted using the inductive method used in the qualitative research method. In studies with insufficient prior knowledge, the collected data are analyzed, and codes are first created. Sub-themes are formed from the codes developed in the following process, and finally, the themes of the research are developed (Yıldırım & Şimşek, 2021). 62 codes were formed from the data analyzed based on the research questions.

Validity and Reliability

All research must present valid and reliable data. This constitutes one of the essential criteria of the research. Validity and reliability in qualitative research are ensured by credibility. Within the scope of this research, different measures were taken for the research paradigm to ensure credibility. These are as follows:

- The whole process, from the beginning to the end of the research, was recorded in the researcher's diary.
- The interview questions prepared for the research were finalized by another expert who has been teaching qualitative research and special education for many years.
- Permissions, such as ethics committee and participant approval, were obtained.
- Each interview was transcribed and sent to the participant for confirmation.
- The interview transcripts were reviewed by another eye to prevent data loss.
- The data obtained were described in detail.
- All the data obtained were kept confidential by adhering to the principle of confidentiality to prevent anyone else from accessing them during the research process.

Results and Discussion

Within the scope of the research, the data collected through interviews, observations, diaries, and documents were analyzed inductively. Sixty-two codes were obtained from the analyzed data. From these codes, four main themes and 12 sub-themes were reached. Information on the main theme and sub-themes is shown in Table 1.

Table 1. Information on the theme and sub-themes.

Main theme	Child Theme
Views on the Diagnosis Process	<i>His experience with the hearing screening test process</i> <i>Views on hearing loss</i>
Mother's Experience with the Process of Using Hearing Assistive Technologies	<i>Opinions on Hearing Aids</i> <i>Having problems with family due to hearing aids</i> <i>Views on the process of getting a cochlear implant</i>
Mother's Views on the Process of Learning That the Child Has an Additional Disability	<i>Mother's views on family life processes after additional disability</i> <i>Opinions of the additional disabled child on the effect of the mother's social relations</i> <i>Opinions of the mother on the educational processes of a child with an additional disability</i> <i>Mother's views on the health-related life of the child with an additional disability</i>
Mother's Views on Her Life in the Process	<i>Regrets of the past</i> <i>Opinions on financial difficulties</i> <i>Opinions on social support</i>

Views on the Diagnosis Process

The audiology department of a university hospital in his province for the newborn hearing screening test. The mother expresses the process experienced by Emre, who could not pass the hearing test when he first went.

"So when Emre was first born, it couldn't pass through one of his ears; my teacher said it went through one. Then they called us four times to hear the newborn; in all four of them, it went through one ear and stayed in one ear. Then we were transferred to Umuttepe."

His experience with the hearing screening test process

The hearing screening test, which Emre went to for the fourth time, revealed that he had hearing loss. To perform the hearing test, especially very young children must be asleep during the test. Regarding this process, the mother expressed it as follows:

"He would be put to sleep there. They told me to sleep, and I said, I mean, not to sleep. That is, he does not stay in a state to sleep for a long time. They gave medicine intravenously, and it became clear in 45 minutes."

Thanks to the newborn hearing screening program put into practice by the Ministry of Health in our country in 2004, it is possible to detect hearing loss with various tests immediately after birth (Genç et al., 2005; Kemaloğlu, 2015).

Views on hearing loss

Emre could not pass the newborn hearing test on his fourth visit. The mother expressed her feelings when she learned the test result as follows:

"Mrs. Merve said, "So many and so many decibels—one was at 85 and the other at 50%. That's how you will be equipped with devices; get a device as soon as possible"."

"When I first learned it, my teacher did not expect it at all. I was shocked. He did not have it in his brother, so there is no family. I cried there; I went alone; I was alone."

Parents who have children with disabilities go through some emotional processes when they learn about their child's inadequacy. Studies examining these processes in the literature define the process as a stage model (Akçamete, 2011; Cavkaytar, 2008; Kearney & Griffin, 2001; O'Shea et al., 2001). The phase model consists of three phases. The first phase is anger, rejection, and depression; the second stage is confusion, guilt, and anger; and the third stage is bargaining, acceptance, and compliance. When the mother learned about Emre's condition, it was seen that she experienced the first phase with the expression *"I was shocked"*. Later, the mother accepted the event, tried to focus on the solution, and adapted to the situation.

"That's how you will be equipped with devices; get a device as soon as possible. We already bought it within a month."

The mother wanted to benefit from hearing aid technologies to minimize hearing loss's effects. In this way, he got over the state of shock he experienced and learned to live with it by accepting the event.

Mother's Experience with the Process of Using Hearing Assistive Technologies

Opinions on Hearing Aids

After the mother learned that the audiologist should purchase a hearing aid, she bought a suitable hearing aid for Emre. The mother described the process related to the hearing aid as follows:

"Well, our devices were not good at all, my teacher, so I went on a recommendation, but they never directed us. Well, I wanted to brand a or something like b*. But they gave us a very different brand. I can't think of the name right now, but I will tell you. I gave them to someone here too. Then he did not benefit from them either. It was so scratchy. The boy is big, and he talks. Arda even studies here. They gave it back to me. Then they are in my hands after they are equipped. That's right, sir."*

The mother thinks that she bought a hearing aid for Emre, but it becomes clear that the device is useless. We can understand that he is doing general research on the devices by giving the device's brand name. Hearing aids or cochlear implant applications are recommended for children with hearing loss, depending on the type and degree of loss (Moeller et al., 2009). According to the mother, Emre's inability to benefit from the hearing aid is as follows:

"So I don't think it's enough. He said to take it to Istanbul. We took him to Kadıköy. Selim Bey greeted us there but said that his devices were out of order. So nothing has been done here."

Hearing aids are used for individuals with milder hearing loss. In determining this, hearing specialists such as ENT specialists and audiologists should be evaluated. Emre could not benefit from the hearing aid due to the type and degree of his loss.

Having problems with family due to hearing aids

The mother stated that she had difficulties due to both the inadequacy of the hearing aid and the lack of moral support from her husband during the process. Regarding this issue, he stated the following:

"This is where we get where we go. For example, they could not mold. Omar's devices were squeaking a lot; that crowing sound made us angry, so let me say that, my teacher. Shut up, my wife was saying, for example."

Mum, shut up; it's always me. It's always me. This time, I couldn't make it home. We were arguing a lot, but sometimes I say it was worth it, teacher."

Having a child with a disability in the family develops negative feelings for family members. In particular, situations such as fathers being unable to support mothers during the process are frequently encountered (Özşenol et al., 2003). The mother states that her husband blames her for the negative aspects of the device. At the same time, he states that he is tired and incapable of being self-sufficient because he has to care for Emre all the time. Mothers of children with disabilities may experience more difficulties than other family members because they are completely involved in the care of their children (Lopez-Wagner et al., 2008).

Emre has used hearing aids for 2.5–3 years. Emre did not see any benefit from the hearing aid. Regarding this, the mother expressed her experiences as follows:

"Two and a half years. Our teacher Kübra always warned us: Emre is not looking. Emre is not looking. I reported this to my wife."

The mother then decided to have cochlear implant surgery for Emre.

Views on the process of getting a cochlear implant

The newborn hearing screening test diagnosed Emre with severe sensorineural hearing loss. The maternal cochlea stated the following regarding the implant decision-making process:

"All of a sudden, my teacher took me upstairs. Emre had such an examination of his ears. Sometimes there was earwax, which they were taking with something, with a device, and he would cry a lot with it. They used to say, We'll take it, Emre; there's nothing we can do. I mean, I said, Ms. Merve, I want her to have surgery. I said it doesn't happen like this; he said, Do you want it? but he said it will be challenging. Let's go, I said I agreed. If he hears it as we do, I said I would agree, so we arranged it immediately."

The mother stated that she decided to have a cochlear implant and convinced her husband as follows:

"My teacher said I don't want it. I mean, how can I give it? he said. I don't work for that much money. I said you would work then. I was a lot too, my teacher. Then I said, I will not listen to you whether you come or not, but I said to disappear in this house when I come. Don't be seen in my eyes; I said everything. Then, on the day of your surgery, my hand and my brother-in-law live there, and they took me to the hospital in Istanbul. I said we, I called, and we went to bed. We're going to have surgery tomorrow; deposit the money."

Numerous research findings in the literature report that the cochlear implant process is performed safely and that the success rate is high (Allen et al., 1998; Hoffman & Cohen, 1995). One of the most important elements of a cochlear implant application is the family's decision. It is important that parents have the appropriate information to base this decision on, which can be highly relevant to the experiences of other parents. Therefore, it is vital to use this experience, use it, and make this information available, considering what is important to parents rather than experts (Archbold et al., 2002). Unfortunately, guidance and information functions are unavailable in most institutions after children are diagnosed with hearing loss. This situation may cause families to be confused about what to do and how to do it, and the prolongation of the process may cause the child to live without auditory input. The mother stated that she learned about the cochlear implant from Emre's conversations with the families at the rehabilitation center he attended. Mothers who have had cochlear implant experience before transfer this information to other mothers. This situation needs to be handled more professionally.

Mother's Views on the Process of Learning That the Child Has an Additional Disability

After the cochlear implant surgery, Emre is taken by his mother to the guidance and research center in his province for an educational diagnosis. After the educational evaluation and diagnosis, Emre was diagnosed with hearing loss, autism, and attention deficit and hyperactivity disorder. Regarding this process, the mother says the following:

"I took Emre, sir. They were evaluated there. Then they called me. They asked questions. They told me that Emre has autism and a communicative disability in addition to hearing loss. I was very surprised there, teacher; I did not expect it at all. I was just saying that he doesn't hear, it turns out there are other things too."

As mentioned, families cannot accept the situation after a disability or disability is diagnosed. The mother expressed shock when she first learned of her hearing loss. He expresses that he experiences the same feelings this time because he has an additional disability. In the literature, no research findings have been found on how families react to other disabilities or inadequacies that occur after a disability. Based on this, every disability or disability diagnosis may cause the processes mentioned in the stage model to be experienced by families. We will pay attention to how long it takes for the family to accept the situation and adapt to the first and second feelings.

Mother's views on family life processes after additional disability

The mother expressed the following regarding the process after Emre received additional disability diagnoses:

"Sir, we did not expect it at all. We thought we weren't talking just because he couldn't hear. I said there is something to the teacher, Pınar. But they didn't pay much attention. His father didn't care much for him because he didn't hear it anyway. He is never even in the same room with him, sir. It's going very hard for me. His brother doesn't play with him anymore either."

We mentioned above that fathers are slower to accept their disabled children than mothers. Here, the situation is similar. While the mother offered all kinds of support for Emre, the fact that the father did not care for her supports similar findings. The biggest supporter of the mother in the process is her husband (Köksal & Kabasakal, 2012).

Mothers who cannot get enough support from their spouses generally get support from their own families (Yıldırım & Akçamete, 2014). The mother states that she cannot get enough support from her husband. He states that he received the greatest support from his mother and siblings during the process.

"My sisters, for example, my mother and father said, "If my daughter is going to hear it right away, why are you waiting?" For example, my brother said that if money is money, we will support him."

The mother and her own family were frequently encountered when we went to the home for observations within the scope of the research. This shows that the support of his family continues.

Opinions of the additional disabled child on the effect of the mother's social relations

The mother, Emre, stated that they could not return to their normal lives after being diagnosed with an additional disability and that she now has problems in social relations with relatives and neighbors.

"I couldn't go anywhere to sit. Am I still like that? I am not. I am more comfortable. For example, I go to visit my nephews. For example, I sit more comfortably with my sisters and sisters now, my teacher."

There are various research findings stating that families with children with disabilities experience problems in their social relations because of their children (Altuğ-Özsoy et al., 2006; Kurt et al., 2008; Wang & Michaels, 2010; Yıldırım & Akçamete, 2014). Especially mothers with additional disabilities or children with multiple disabilities state that they have problems with their environment and can only go to their own families (Kizir & Tekinarslan, 2018). Here, he can understand from the mother's expressions that he can only go to his sister and mother. Apart from this, it is seen that he cannot maintain positive relations with relatives or neighbors.

Opinions of the mother on the educational processes of a child with an additional disability

The mother expressed her feelings about Emre's education process as follows:

"Sir, we come here on certain days of the week. But I don't know, so I can't say anything if you say we are very good. Omer doesn't make a sound. He attends so many classes, but sometimes he just shouts and calls. But at least there is a language problem, nothing else."

"...and very few teachers are in training. So it seems little to us."

From the mother's statement, it can be interpreted that Emre had expectations that he should at least have literacy experience while he went to school. He thinks that the training is insufficient due to its content and duration. In our country, the number of institutions providing education to children with special hearing loss is quite low. Apart from this, most children are included in inclusive education in special education classes or general education classes. Emre was not accepted to any kindergarten education because he has an additional disability and is receiving supportive education in the rehabilitation center. There are research findings that the education processes of families with additional disabled children are insufficient (Kizir & Tekinarslan, 2018; Yıkımsı & Özbey, 2009). Various field experts should act together to meet the educational needs of children with additional disabilities from an early age (Şafak, 2013). Since Emre has been diagnosed with autism and attention deficit and hyperactivity disorder in addition to hearing loss, the education process should be continued in cooperation with a special education teacher, a speech-language therapist, an educational audiologist, and, if necessary, pedagogues. When these multiple obstacles come together, problems such as social skills and early literacy skills that the child should acquire in the early years may cause problems in the future.

Mother's views on the health-related life of the child with an additional disability

The mother expressed the health problems she had and the problems she had experienced with those problems as follows:

"After Emre was diagnosed with ADHD, I did some research. Doctors gave medicine. I am using the medicine. Even though it doesn't seem like much use, I will leave it. I couldn't go for him."

Emre can be very sick. I have to be very careful. He has to be under constant surveillance here and there, in the park, in the shopping center, at school, and by my teacher. There is also a device; if something happens to it, we will have to buy it expensively, again with a lot of expenses. His father sometimes takes him to the park. I call and ask how."

I call and ask how."

In the mother's statement, she may have problems with Emre himself. Especially families with children with disabilities have mothers, and they complain that they do not have time to breathe and rest because of the constant care of their children (Redmond & Richardson, 2003). In addition, drug treatment applications are widely used in children diagnosed with ADHD (Faraone et al., 2008; Spetie & Arnold, 2007; Tura, 2022).

Mother's Views on Her Life in the Process

The mother has gone through various lives in the process. These experiences are presented in sub-themes as follows:

Regrets of the past

During the interview, the mother stated that she had some regrets about the past, as follows:

"So, master. Sometimes I wish I hadn't gotten married. There are times when I ask myself why. For a while, I was thinking about this often and asking myself."

When this finding is compared with previous research findings, it becomes a finding specific to the current research. When other research findings in the literature are examined, it is seen that parents' regrets are only punishment for an evil they have done long before their child's disability (İçmeli et al., 2008). The mother regrets that her husband left her alone in the process. He states that he finds solutions to all the problems he encounters and receives support from his sisters and mother.

Opinions on financial difficulties

The mother states that she has had a constant problem coping with economic problems since the birth of her child.

"Hodja, my wife, was working with a butcher at first. Already a primary school graduate, I am now a high school graduate. Now he goes to clean the buildings. He's doing it in the doorway, by the way. But he earns very little, my teacher. We need a lot, so it's not enough; I can't get enough."

"The state gives a disability pension to Emre, sir. I'm already trying to meet many of Emre's needs. That is, if we look at my wife, I cannot do anything for the child, my teacher."

Financial difficulties can be a problem experienced by almost all families with disabled children. In most studies, this problem is expressed by families (Akçamete, 2011; Lafçı et al., 2014; Redmond & Richardson, 2003). In our country, a certain monthly salary is paid to families with disabled children by the Ministry of Family and Social Policies. The mother takes the disability pension given to Emre and uses all of this money to meet Emre's needs.

"You already know that this is a high-place village. The nearest place is 15–20 minutes away from the bus. I can walk, but it is difficult for Emre to walk. I also call a taxi sometimes. After all, I'm spending his money on him."

"I get play therapy; Emre has a salary; I pay it from there."

As above, the mother spends all the money given to Emre on things related to Emre.

Opinions on social support

The mother constantly expressed that she wanted to receive psychological support during the process and had self-destructive thoughts related to this.

"Sometimes, that's why I don't want to go anywhere. I've passed it, and I'm not the same anymore. What if those things survive? For example, I wanted to talk to the psychologists, psychiatrists, and psychologists here. Like for myself. He said, "Well, we are looking after the children." A friend of mine said that there is one for adults as well. That said, I do not recommend this place. You went to another doctor, and you went to the hospital, I made an appointment there. That day was also the day of the health professionals, which was not lucky; my teacher and I did not go. I was upset because I was very upset about Ömer, so my teacher. How can I say? I've been acting like this myself; I have a speech disorder. My speech thing is broken. I was talking nervously, and everyone says so. Is it because you don't understand Ömer? Is it because it's full now? Said."

"My brother said, for example, that you are speaking very angrily."

"But teacher, sometimes I get full, so I scream. So I'm not hiding it. I'm so bored. So I'm sitting, crying."

"I said if you did what I did, you would commit suicide."

The mother expressed the situation given by the process as above. In particular, you think that suicide is perhaps an expression that should be taken into account. It is stated that mothers who cannot receive social support, especially in families with disabled children, struggle to cope with the problems they experience. As a result, they often manage the process negatively. It was concluded that mothers who received social support were more positive about solving problems (Coşkun & Akkaş, 2009). Families with disabled children in our country need social support occasionally during the process. Social support should include getting information, guidance, and psychological support. Families usually do what they know how to do when they are alone, and this can often cause negativity. The mother made some applications but stated that she could not receive any psychological support. At the same time, it is seen that the support education institution gives no education, such as the family education that Emre went to.

Add results and findings here. Add results and findings here. Add results and findings here. Add results and findings here. Add results and findings here. Add results and findings here. Add results and findings here. Add results and findings here. Add results and findings here.

Conclusion

This study aimed to examine the life story of the mother of a child with additional disabilities such as hearing impairment, autism, and ADHD based on her statements. The data collected for this purpose were analyzed, and findings were obtained in parallel with the literature. As a result, it is surprising that no program or model includes the diagnosis, evaluation, and education processes of children with additional disabilities in our country. Especially if families do not know what to do in this process, it can make the situation even more

difficult. Although families try to find some solutions within their means, these solutions do not help ensure continuity.

Recommendations

The mother stated that the biggest difficulty was that her husband did not support her. Psychological support can be provided, especially to families with disabled children, after the diagnosis, and families can overcome the situation together. Spouse therapies can be organized, and family pieces of training can be planned on which tasks the spouses should do and how.

The mother's lack of knowledge about the additional disability and feeling inadequate about what to do in the process are also supported by other research findings. In this case, the Ministry of National Education and universities can cooperate to train more experts in the field, especially on multiple disabilities. Academics who are experts in multiple disabilities can increase their knowledge through various in-service trainings for teachers working with children with special needs in rehabilitation centers that provide supportive education.

In conclusion, families, especially mothers, state that they need information and social support the most. Having services to inform families about the diagnosis, evaluation, and other processes of children with special needs can help them positively get through the process. The content of social support programs to be offered to families can be further expanded, and support services can be provided to mothers with more experts.

Author (s) Contribution Rate

The authors contributed equally to the paper.

Conflicts of Interest

The authors declare that they have no conflicts of interest.

Ethical Approval (only for necessary papers)

This research was conducted with the permission of the Bolu Abant İzzet Baysal University Human Research Ethics Committee in Social Sciences, with the decision numbered 2022/441 at the 2022/12 meeting dated November 26, 2022.

References

- Akçamete, G., (Ed.). (2011). *Özel Gereksinimi Olan Küçük Çocuklar*. (1. Basım) [Young Children with Special Needs. (1st Edition).]Ankara: Nobel
- Allen, M. C., Nikolopoulos, T. P., & O'Donoghue, G. M. (1998). Speech intelligibility in children after cochlear implantation. *The American Journal of Otolaryngology*, 19(6), 742-746. <https://pubmed.ncbi.nlm.nih.gov/9831147/>
- Altuğ-Özsoy, S., Özkahraman, Ş., & Çallı, F. (2006). Zihinsel engelli çocuk sahibi ailelerin yaşadıkları güçlüklerin incelenmesi [Review of hardships undergone by families with mentally retarded children]. *Journal of Social Policy Studies*, 9(9), 69-77. <https://dergipark.org.tr/tr/pub/spcd/issue/21102/227266>
- Archbold, S. M., Lutman, M. E., Gregory, S., O'Neill, C., & Nikolopoulos, T. P. (2002). Parents and their deaf child: their perceptions three years after cochlear implantation. *Deafness & Education International*, 4(1), 12-40. <https://doi.org/10.1179/146431502790560962>
- Bahçivanoğlu-Yazıcı, A., & Akçin, N. (2014). Çoklu yetersizliği olan çocukların annelerinin çocuklarının gelişimlerine ilişkin görüşlerinin betimlenmesi [Describing mother's opinions about development process of their children with multiple disability]. *Ahi Evran Üniversitesi Kırşehir Eğitim Fakültesi Dergisi (KEFAD)*, 15(2), 335-356. <https://dergipark.org.tr/tr/download/article-file/1490009>
- Barnett, W. S., & Boyce, G. C. (1995). Effects of children with Down syndrome on parents' activities. *American Journal of Mental Retardation: AJMR*, 100(2), 115-127. <https://eric.ed.gov/?id=EJ510104>
- Bogdan, R., & Biklen, S. K. (1997). *Qualitative research for education*. (third ed.) Boston, MA: Allyn & Bacon.
- Bruce, S. M. (2011). Severe and multiple disabilities. In Kauffman, J.M. & Hallahan, D.P. (Ed.) *Handbook of special education* (pp. 291-303). New York and London: Routledge

- Cavkaytar, A. (2008). Perspectives of Turkish Mothers on Having a Child with Developmental Disabilities. *International Journal of Special Education*, 23(2), 101-109. <https://hdl.handle.net/11421/10776>
- Clandinin, D. J., & Connelly, F. M. (2000). *Narrative inquiry: Experience and story in qualitative research*. San Francisco: Jossey-Bass
- Clandinin, D. J. (2006). Narrative Inquiry: A Methodology for Studying Lived Experience. *Research Studies in Music Education*, 27(1), 44–54. <https://doi.org/10.1177/1321103X060270010301>
- Clark, R. E., & Drake, R. E. (1994). Expenditures of time and money by families of people with severe mental illness and substance use disorders. *Community Mental Health Journal*, 30, 145-163.
- Creswell, J. W. (2012). *Educational research: Planning, conducting, and evaluating quantitative and qualitative research* (4th ed.). USA: Sage
- Davis, N. O., & Carter, A. S. (2008). Parenting stress in mothers and fathers of toddlers with autism spectrum disorders: Associations with child characteristics. *Journal of Autism and developmental disorders*, 38, 1278-1291. <https://doi.org/10.1007/s10803-007-0512-z>
- Eldeniz Çetin, M. (2013). *Ağır ve çoklu yetersizliği olan bireylerin tercihlerinin değerlendirilmesi ve seçim yapma becerisinin öğretimi [Preference assessment in individuals with profound and multiple disabilities and teaching choice-making]*. Eğitim Bilimleri Enstitüsü, Ankara.
- Ersoy, A., & Bozkurt, M. (2017). Understanding an elementary school teachers' journey of using technology in the classroom from sand table to interactive whiteboard. *International Electronic Journal of Elementary Education*, 8(1), 1–20. Retrieved from <https://iejee.com/index.php/IEJEE/article/view/94>
- Faraone, S. V., Biederman, J., Morley, C. P., & Spencer, T. J. (2008). Effect of stimulants on height and weight: a review of the literature. *Journal of the American Academy of Child & Adolescent Psychiatry*, 47(9), 994-1009. <https://doi.org/10.1097/CHI.ObO13e31817eOea7>
- Farrell, A. F., & Krahn, G. L. (2014). Family life goes on: Disability in contemporary families. *Family relations*, 63(1), 1-6. <https://doi.org/10.1111/fare.12053>.
- Gallaudet Research Institute. (2003). *Regional and national summary report of data from the 2002-2003 annual survey of deaf and hard of hearing children & youth*. Washington, DC: GRI, Gallaudet University.
- Genç, A. G., Ertürk, B. B. & Belgin, E. (2005). Newborn hearing screening: From the beginning to the present. *Journal of Child Health and Diseases*, 48,109-118. http://www.cshd.org.tr/uploads/pdf_CSH_137.pdf
- Giangreco, M.F. (2006). Foundational concepts and practices for educating students with severe disabilities. In M.E. Snell & F. Brown (Eds.). *Instruction of students with severe disabilities* (6th ed., pp. 1-27). Upper Saddle River, NJ: Pearson Education/Prentice-Hall.
- Glesne, C. (2013). *Nitel araştırmaya giriş[Introduction to qualitative research]*. A. Ersoy ve P. Yalçinoğlu (Çev. Edt.). Ankara: Anı Yayıncılık
- Graungaard, A. H., & Skov, L. (2007). Why do we need a diagnosis? A qualitative study of parents' experiences, coping and needs, when the newborn child is severely disabled. *Child: Care, Health and Development*, 33(3), 296-307. <https://doi.org/10.1111/j.1365-2214.2006.00666.x>
- Gray, D. E., & Holden, W. J. (1992). Psycho-social well-being among the parents of children with autism. *Australia and New Zealand Journal of Developmental Disabilities*, 18(2), 83-93. <https://doi.org/10.1080/07263869200034841>
- Güler, A., Halıcıoğlu, M. B. ve Taşğın, S. (2015), *Sosyal bilimlerde nitel araştırma* (2. Baskı). [Qualitative research in the social sciences (2nd Edition)] Ankara: Sözkese Matbaacılık
- Hallahan, D. P., Kauffman, J. M., & Pullen, P.C. (2018). *Exceptional learners: an introduction to special education (14th ed.)*. Pearson Education, Inc
- Harrison, M., Roush, J. & Wallace, J. (2003). Trends in age of identification and intervention in infants with hearing loss. *Ear and Hearing Issue*, 24(1),89-95. <https://doi.org/10.1097/01.AUD.0000051749.40991.1F>
- Hill, M. G. (2015). *Aklımın aklı: Psikoloji [Psychsmart]* (Translation from 2nd Edition. Mithat Durak, Emre Şenol Durak, Ufuk Kocatepe). Ankara: Nobel.
- Hintermair, M. (2000). Children who are hearing impaired with additional disabilities and related aspects of parental stress. *Exceptional Children*, 66(3), 327-332. <https://doi.org/10.1177/001440290006600304>

- İçmeli, C., Ataoğlu, A., Canan, F. & Özçetin, A. (2008). Comparison of child bringing-up attitudes of families having mentally retarded children and families who have healthy children. *Düzce Medical Journal*, 10 (3), 21-28. Retrieved from <https://dergipark.org.tr/en/pub/dtfd/issue/48265/610990>
- İnce, M., & Yıkılmış, A. (2021). Opinions and recommendations of academics training special education teachers about applicability of integration in Turkey. *International Education Studies*, 14(11), 54-74. <https://doi.org/10.5539/ies.v14n11p54>
- İnce, M., Kösetaş, B. & Ataman, A.S. (2022, Kasım). *Understanding a mother with a child with special needs: A narrative research "In Memory of the 100th Anniversary of the Great Victory" 4th International Congress of Turkish World Educational Sciences and Social Sciences*, Antalya. <https://drive.google.com/file/d/18qfOfIPxIy7qoxGDDovtAJkXYtbNIedo/view>
- Karabulut, A. & Taviş, Y. Z. (2016). Zihin engellilere kardeş aracılığıyla sunulan öğretim programının oyun kurallarının öğretiminde etkililiği. *Abant İzzet Baysal University Faculty of Education Journal*, 16 (3) , 884-901 . Retrieved from <https://dergipark.org.tr/en/pub/aibuefd/issue/24917/263018>
- Karadağ, G. (2009). Engelli çocuğa sahip annelerin yaşadıkları güçlükler ile aileden algıladıkları sosyal destek ve umutsuzluk düzeyleri [Hardships undergone by mothers with handicapped children, hopelessness and social support from family]. *TAF Preventive Medicine Bulletin*, 8(4), 315-322. <https://search.trdizin.gov.tr/yayin/detay/96764/>
- Kearney, P. M., & Griffin, T. (2001). Between joy and sorrow: Being a parent of a child with developmental disability. *Journal of Advanced Nursing*, 34(5), 582-599. <http://dx.doi.org/10.1046/j.1365-2648.2001.01787.x>
- Kemaloglu, Y.K. (2015). Newborn hearing screenings. E. Belgin and A. S. Şahlı (Ed.), in *Basic Audiology* (p.191-217). Ankara: Güneş Medical Bookstores.
- Kızır, M., & Çifci Tekinarslan, İ. (2018). Determining the problems and the methods of coping with the problems of the mothers of children with severe disabilities. *Ankara University Faculty of Educational Sciences Journal of Special Education*, 19(2), 233-256. <https://10.21565/ozelegitimdergisi.321683>
- Köksal, G., & Kabasakal, Z. (2012). The examination of predicting factors of perceived stress of parents with mentally retarded children. *Dokuz Eylül University Buca Faculty of Education Journal*, (32), 71-91. <https://dergipark.org.tr/tr/pub/deubefd/issue/25119/265246>
- Kurt, A. S., Tekin, A., Koçak, V., Özpulat, Ö., & Önat, H. (2008). Zihinsel engelli çocuğa sahip anne babaların karşılaştıkları güçlükler [Living difficulties for parents of children with mental disability]. *Türkiye Klinikleri Journal of Pediatrics*, 17(3), 158-163. <https://www.turkiyeklinikleri.com/article/en-zihinsel-engelli-cocuga-sahip-anne-babalarin-karsilastiklari-guclukler-52736.html>
- Lederberg, A. R., & Golbach, T. (2002). Parenting stress and social support in hearing mothers of deaf and hearing children: A longitudinal study. *Journal of deaf studies and deaf education*, 7(4), 330-345. <https://doi.org/10.1093/deafed/7.4.330>
- Lopez-Wagner, M., Hoffman, C., D., Sweeney, D., P., Hodge, D., & Gilliam, J. (2008). "Sleep problems of parents of typically developing children and parents of children with autism", *The Journal Of Genetic Psychology*, 169 (3): 245-260. <https://doi.org/10.3200/GNTP.169.3.245-260>
- Luijckx, J., Van der Putten, A. A. J., & Vlaskamp, C. (2017). Time use of parents raising children with severe or profound intellectual and multiple disabilities. <http://doi:10.1111/cch.12446>
- McIntyre, L., Kraemer, B. R., Blacher, J., & Simmerman, S. (2004). Quality of life for young adults with severe intellectual disability: Mothers' thoughts and reflections. *Journal of Intellectual and Developmental Disability*, 29(2), 131-146. <https://eric.ed.gov/?id=EJ681075>
- Mencap. (2001). *No ordinary life: The support needs of families caring for children and adults with profound and multiple disabilities*. London: Royal Society for Mentally Handicapped Children and Adults.
- Moeller, M. P., Hoover, B., Peterson, B., & Stelmachowicz, P. (2009). Consistency of hearing aid use in infants with early-identified hearing loss. *American journal of audiology*, 18(1), 14-23. [https://doi.org/10.1044/1059-0889\(2008/08-0010\)](https://doi.org/10.1044/1059-0889(2008/08-0010))
- Nakken, H., & Vlaskamp, C. (2007). A need for a taxonomy for profound intellectual and multiple disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 4, 83-87. <https://doi.org/10.1111/j.1741-1130.2007.00104.x>

- O'Shea, D. J., & Hammitte, D. J. (2001). *Families and teachers of individuals with disabilities: Collaborative orientations and responsive practices*. Allyn & Bacon.
- Özşenol, F., Işıkhhan, V., ve Ünay, B. (2003). The evaluation of family functions of families with handicapped children., *Gülhane Medical Journal*, 45 (2): 156-164. <https://search.trdizin.gov.tr/tr/yayin/detay/20860>
- Redmond, B., & Richardson, V. (2003). Just getting on with it: Exploring the service needs of mothers who care for young children with severe/profound and life-threatening intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 16(3), 205-218. <https://doi.org/10.1046/j.1468-3148.2003.00165.x>
- Sardohan-Yıldırım, E. S., & Akçamete, G. (2014). Determining the difficulties faced by mothers of children with multiple disabilities in the process of early childhood special education services. *Cumhuriyet International Journal of Education*, 3(1), 74-89. <https://doi.org/10.30703/cije.321336>
- Sardohan-Yıldırım, A.E., & Vezne, R. (2022). A Family Education Intervention for Parents Having Children with Multiple Disabilities during COVID-19. *International Journal of Contemporary Educational Research*, 9(1), 179-190. <https://doi.org/10.33200/ijcer.1004241>
- Seltzer, M. M., Greenberg, J. S., Floyd, F. J., Pettee, Y., & Hong, J. (2001). Life course impacts of parenting a child with a disability. *American Journal On Mental Retardation*, 106(3), 265-286. [https://10.1352/0895-8017\(2001\)106<0265:LCIOPA>2.0.CO;2](https://10.1352/0895-8017(2001)106<0265:LCIOPA>2.0.CO;2)
- Seggie, F. N. ve Bayyurt, Y. (2015). *Nitel Araştırma Yöntem, Teknik, Analiz ve Yaklaşımları*. [Qualitative Research Methods, Techniques, Analysis and Approaches]. Ankara: Anı Yayıncılık.
- Sloper, P., & Turner, S. (1992). Service needs of families of children with severe physical disability. *Child: Care, Health and Development*, 18(5), 259-282. <https://doi.org/10.1111/j.1365-2214.1992.tb00359.x>
- Şafak, P. (2013). *Ağır ve çoklu yetersizliği olan çocukların eğitimi* [Education of children with severe and multiple disabilities] (2. baskı). Ankara: Vize Yayıncılık.
- Şen, E. (2004). *Engelli çocuğu olan ailelerin yaşadığı güçlükler* [Difficulties of families with disabled child] (Unpublished master's thesis, Mersin University, Institute of Health Sciences, Mersin, Turkey). Retrieved from <http://tez.yok.gov.tr/UlusalTezMerkezi>. (Thesis Number 156345)
- Tadema, A. C., & Vlaskamp, C. (2010). The time and effort in taking care for children with profound intellectual and multiple disabilities: A study on care load and support. *British Journal of Learning Disabilities*, 38, 41-48. <https://doi.org/10.1111/j.1468-3156.2009.00561.x>
- Tura, G. (2022). The Effect of Psychoeducation Program Based on Structural Family System Therapy on Family Functionality in Families of a Child Diagnosed with Attention Deficit Hyperactivity Disorder. *International Journal of Contemporary Educational Research*, 9(1), 164-178. <https://doi.org/10.33200/ijcer.1026579>
- Van Timmeren, E. A., Van der Putten, A. A. J., Schroyensteen Lantman-de Valk, H. M. J., Schans, C. P., & Waninge, A. (2016). Prevalence of reported physical health problems in people with severe or profound intellectual and motor disabilities: A cross-sectional study of medical records and care plans. *Journal of Intellectual Disability Research*, 60, 1109-1118. <http://doi:10.1111/jir.12298>
- Wake, M., & Carew, P. (2016). Science, not philosophy, will help deaf and hard-of-hearing children reach their potential. *Pediatrics*, 137(1), e20153443. <https://doi.org/10.1542/peds.2015-3443>.
- Wang, P., & Michaels, C. A. (2010). Chinese families of children with severe disabilities: Family needs and available support. *Research and Practice for Persons with Severe Disabilities*, 34(2), 21-32. <https://doi.org/10.2511/rpsd.34.2.21>
- Westling, D., & Fox, L. (2009). *Teaching students with severe disabilities* (3rd ed.). Upper Saddle River, NJ: Merrill.
- Yıkıncı, A., & Özbey, F. Y. (2009). Otistik çocuğa sahip annelerin çocuklarının devam ettiği rehabilitasyon merkezlerinden beklentilerinin ve önerilerinin belirlenmesi [Define the expectations of mothers whose autistic children attends to a rehabilitation center]. *International Online Journal of Educational Sciences*, 1(1), 124-153. <https://www.ajindex.com/dosyalar/makale/acarindex-1423904513.pdf>
- Yıldırım, A., & Şimşek, H. (2021). *Sosyal Bilimlerde Nitel Araştırma Yöntemleri* (12 baskı) [Qualitative Research Methods in Social Sciences](12th ed.) Seçkin. Ankara
- Zaidman-Zait, A. (2007). Parenting a child with a cochlear implant: A critical incident study. *Journal of Deaf Studies and Deaf Education*, 12(2), 221-241. <https://doi.org/10.1093/deafed/enl032>