



Living with My Intellectually Disabled Sibling: A Qualitative Research Zihinsel Engelli Kardeşimle Yaşamak: Nitel Bir Araştırma

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Abstract

This study aims to identify the life experiences of individuals who have intellectually disabled siblings and their views on this situation. 10 individuals participated in the study. The design of this study is qualitative research; we used a semi-structured interview form for data collection. Ethical approval of the study and individual consent of the participants was obtained. We performed a thematic analysis in analysing the data. We conducted the study under three categories: thinking, emotion/behaviour and coping; and eight main themes: having a disabled sibling, thoughts about the attitude of people around, feelings about having a disabled sibling, the way of showing love to the disabled sibling, experiencing difficulties in the family, experiencing difficulties in making explanations to the people around, practices they perform in the face of difficulties. Although having an intellectually disabled sibling is challenging for the non-disabled sibling, it is also enabling them to gain maturity and developmental features.

Keywords: Intellectual disability, sibling, qualitative study.

Öz

Bu çalışma, zihinsel engelli kardeşi olan bireylerin yaşam deneyimlerini ve bu duruma ilişkin görüşlerini belirlemeyi amaçlamaktadır. Araştırmaya 10 kişi katılmıştır. Bu çalışmanın tasarımı nitel bir araştırmadır; veri toplamak için yarı yapılandırılmış görüşme formu kullanılmıştır. Araştırmanın etik onayı ve katılımcıların bireysel onamları alınmıştır. Verilerin analizinde tematik analiz yapılmıştır. Araştırma üç kategoride gerçekleştirilmiştir: düşünme, duygu/davranış ve başa çıkma ve sekiz ana tema: engelli kardeşe sahip olmak, çevredekilerin tutumlarına ilişkin düşünceler, engelli kardeşe sahip olmakla ilgili duygular, engelli kardeşe sevgi gösterme şekli, aile içinde yaşanan zorluklar, çevredekilere açıklama yapmada zorluk yaşanması, zorluklar karşısında yaptıkları uygulamalardır. Zihinsel engelli bir kardeşe sahip olmak, engelli olmayan kardeş için zorlayıcı olsa da aynı zamanda onun olgunluk ve gelişimsel özellikler kazanmasını da sağlamaktadır.

Anahtar sözcükler: Zihinsel engelli, kardeş, nitel çalışma.

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Introduction

Intellectual disability is a condition in which the intellectual skills of the individual are below normal; and it is a condition where there are inadequacy and disorder in the ability to provide self-care, to continue their life without support, communication skills, school success health and safety (İçmeli et al., 2015). Having a disabled sibling affects the emotional and psychosocial development of individuals. But these developmental processes are important in regulating their relationship with the disabled sibling. The age and level of development of the child with normal development affect their attitude and behaviour towards their sibling (Üstdağ & Bumin, 2014). In a study conducted with individuals who have a disabled sibling, it was stated that the majority of typically developing children with a disabled sibling did not have enough information about their sibling's disability and that they were not given enough explanations about it. Participants stated that, over time, their feelings toward their disabled siblings changed in a positive direction. Moreover, the study emphasized that the problematic behaviors exhibited by their siblings had a negative impact on their lives, and that they felt sadness due to society's negative attitudes toward individuals with disabilities. (Kahraman & Karadayı, 2015).

Mothers and fathers are more concerned with the physical health of healthy siblings and mostly ignore their emotional problems (Er, 2006). This causes emotional and behavioural problems in siblings with normal development (Yavuz & Coşkun, 2014). A study the siblings of children with autism found that siblings of children with autism show more problems than children with healthy siblings (Erden & Akçakın, 2001). It is stated that the addition of a disabled individual to the family increases the stress level in family members and additional responsibilities are imposed on normally developing healthy siblings (Benson & Karlof, 2008). In a study conducted in our country, it was found that there is a significant relationship between emotional burden and depression levels in individuals with a sibling with special needs (İnanç et al., 2024).

The birth of a disabled child can affect the feelings, thoughts and behaviours of all family members. Siblings of intellectually disabled children are the most neglected group. In addition to the studies in the literature that address the difficulties experienced by individuals with a disabled sibling, some studies address non-disabled siblings' participation in the care of disabled siblings (Atkin & Tozer, 2014). The literature states that parents have difficulty caring for a disabled child and siblings provide support at this point (Coyle et al., 2014) and develop closer relationships with their siblings (Burke et al., 2012; Heller & Kramer, 2009). In a study conducted by Türkoğlu (2023), it was stated that individuals who have siblings with special needs experience higher levels of stress and fatigue due to increased caregiving responsibilities, which in turn elevates the risk of depression. Similarly, Kuru-Akçeken (2024) indicated that these individuals often experience social isolation, which serves as a contributing factor to the development of depressive feelings.

Effective psychological practices can lead to the improvement of social interactions of children with disabled siblings, to cope with their emotional and behavioural problems, to increase their self-esteem and to increase the adaptation with the environment. Although there are studies on the effects of the current situation on parents for illnesses that require care burden, studies on siblings, an important part of the family, are highly limited. People with disabilities are among the vulnerable groups, it is important to define the difficulties experienced by disabled individuals and their families, and to make planning and interventions in this regard, within the scope of protecting and improving the mental health of the community. In this context, we conducted this study to identify the attitudes and behaviours of normally developing individuals with mentally disabled siblings toward their disabled siblings and to find out their feelings and thoughts about having a disabled sibling.

Materials and Methods

Research Model

The research is a qualitative, descriptive case study. Case study is based on interpretive, postmodern, semanticist philosophy of science (Yıldırım & Şimşek, 2016). In a case study, a research topic with defined boundaries is described and analyzed in detail in its real environment (Creswell, 2016). For this reason, the study was conducted in a descriptive case study design since it included the views of normally developing siblings on having a sibling with intellectual disabilities.

Collection of Data

We used snowball sampling, “one of the purposeful sampling methods, which is one of the qualitative research method sampling methods”, in the study. Ten volunteers who accepted to participate in the study signed an informed consent form. The interviews were held in their homes where they would feel comfortable. It was interviewed face to face with the participants. In collecting the data, we used an information form consisting of 19 questions including sociodemographic information before the study; and a semi-structured information form consisting of 8 questions that shaped the course of the interview and assisted in gathering relevant information during the interview. While creating the semi-structured interview form, we examined the relevant literature and presented the form to two experts in the field of the form. We obtained participants’ approval to record the interviews. We recorded the interviews with a tape recorder; each interview lasted about 30-40 minutes.

Semi-structured interview form questions:

- Could you share your thoughts about your sibling’s disability?
- Does having disabled siblings cause difficulties in family processes? How do you overcome difficulties?
- Do you have difficulty in explaining the condition of your sibling to the people around you?
- How do the people around you approach your sibling with a disability? How does it affect you?
- How would you express your love for your sibling?
- Could you share activities you like to do with your sibling?
- Have you had any negative experiences with your sibling?
- What do you think having an intellectually disabled sibling feels like? Why?

Ethical Permission

We obtained written consent from individuals who agreed to participate in the study. We made voice recording during the interviews with the permission of the interviewees. We obtained ethics committee approval for the study from the Akdeniz University Clinical Research Ethics Committee, with decision number 70904504/48. All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. This research is funded by the Scientific Research Projects Coordination Unit of Akdeniz University (Project code: TSA-2020-5322).

Analysis of Data

In analysing the data, we used the NVIVO 12 package program and analyzed the data obtained from the interview. Each researcher evaluated theming within the scope of validity and reliability independently and then evaluated it together. We subjected theming to KAPPA and found the KAPPA analysis as 0.944. We used the SPSS 23.0 package program for analysis of the sociodemographic data of the participants. We presented descriptive statistics as number, average and percentage.

Results

The age average of participants in the study is 22.80. We observed that 90% of the participants are women, 60% are university graduates, 60% are not working, the income and expenses of 90% are equal to each other, and 50% live with their families. The age average of intellectually disabled siblings is 16.30, and 70% are girls. We found out that all of the participants communicated with their intellectually disabled siblings.

We divided the qualitative data of this study into three categories under the headings of thinking, emotion/ behaviour, difficulties and coping; and eight main themes: thoughts about having a disabled sibling, thoughts about the attitude of people around, feelings about having a disabled sibling, the way of showing love to the disabled sibling, experiencing difficulties in the family, experiencing difficulties in making explanations to the people around, negative situations with siblings, practices they perform in the face of difficulties. We present an overview of the main themes and sub-themes identified in the study, grouped under the categories of thought, emotion/behaviours, difficulties, and coping methods related to having a disabled sibling (see Table 1).

We coded each participant with a 'P' and wrote a number next to the P to indicate to whom the expression belongs to.

Thoughts about Having a Disabled Sibling

The main theme of the participants opinions about having a disabled sibling is expressed under the six sub-themes of “difficult but acceptable” (P1, P2, P6, P7, P8, P9, P10), “a difficult situation to share” (P4) “a situation that affects future plans” (P1, P4), “a situation that causes anxiety due to genetic predisposition” (P3), “a situation that requires constant care” (P5, P6, P10), “situation that enables one to develop and mature” (P3, P6)”. Participants’ sample expressions are as follows;

The situation is not unusual for us. I have two siblings, and they are the same to me. That's why it's not that different. (P1)

...My sibling has a syndrome due to an abnormality in the fourth chromosome. So my sibling is a very active child in terms of the characteristics of the syndrome. Also, my sibling has a situation where his emotions change very quickly. So living with him is a bit difficult, but in a sense, enjoyable. (P3)

I am very upset about my sibling's disability; when I was in high school, I didn't want to talk about it when people asked about it... This is why I didn't want to tell anyone, and I had a hard time whenever I opened up about it. (P4)

It teaches so much. I was in middle school or something. All responsibilities were assigned to me at an early age due to him; I am glad they did. I think that I matured early on. My mother had to take care of my sibling all the time. (P6)

Thoughts about the Attitudes of the People Around

The main theme of participants’ thoughts about the attitudes of the people around is expressed under the five themes of “uneasy approach” (P1, P2, P3, P6, P8)”, “not wanting to communicate” (P1, P2, P3, P4, P5), “acceptance” (P2, P4, P5, P6, P7, P8, P9, P10), “pity” (P3), “worry” (P3, P4, P5), “criticism (P7)”. Participants’ sample expressions are as follows;

A person who is not informed about the situation can affect us. For example, if they don't know how a child with Down's syndrome acts, reacts or gets happy, it can affect us. If you explain his situation first and tell others that he is immediately distracted by games, there is no problem.(P1)

Table 1. Main Themes and Sub-Themes of Participants in the Thought, Emotion, Behaviour, Difficulties and Coping Methods Categories Related to Having a Disabled Sibling

Category	Main Theme	Sub-Theme
Thought	Thoughts about having a disabled sibling	Difficult but acceptable (P1, P2, P6, P7, P8, P9, P10) A difficult situation to share (P4) A situation that affects future plans (P1, P4) A situation that causes anxiety due to genetic predisposition (P3) A situation that requires constant care (P5, P6, P10) A situation that enables one to develop and mature (P3, P6)
	Thoughts about the attitudes of the people around	Uneasy approach (P1, P2, P3, P6, P8) Not wanting to communicate (P1, P2, P3, P4, P5) Acceptance (P2, P4, P5, P6, P7, P8, P9, P10) Pity (P3) Worry (P3, P4, P5) Criticism (P7)
Emotion/ Behaviour	Emotions about having a disabled sibling	Sadness (P1, P2, P3, P6, P10) Anger (P2, P5, P8) Embarrassment (P2) Love (P3, P6, P8, P9, P10) Increased sense of responsibility (P3, P4, P5, P6) Dissociation (P4)
	Way of showing love to the sibling	To hug (P1, P2, P3) To spare some time (P1, P3) To care about their wishes (P1, P3, P4) To love (P4, P5, P6, P7, P8, P9, P10)
Difficulties and Coping	Having difficulties in family processes	Limited participation in social activities as a family (P1, P2, P4, P6, P9) Requiring sharing of responsibilities (P1, P3, P4) Difficulty controlling the compulsive behaviour of the disabled person (P2, P3, P5, P7, P9) A situation that causes family conflicts (P2) A situation that wears out the caregiver (P2, P3, P5, P6, P8, P10) Setting their needs aside because the priority is given to the disabled sibling (P3) Having difficulty due to people around excluding the disabled sibling (P5) A situation that limits one's own life (P8)
	Having difficulty explaining the situation to the people around	A situation that is more difficult when one is young and easier as one gets older (P1) Having difficulty in expressing opinions when someone asks about the situation (P1, P2, P3, P7, P8, P9, P10) Not wanting to share (P4, P5, P6)
	Negative situations with the sibling	Inability to control compulsive behaviour (P1, P2, P3, P4, P5, P6, P8, P9, P10) Not being able to spend enough time with the mother (P3) Having difficulty in communication (P7)
	Actions done in the face of difficulties	Sharing responsibility (P1, P5, P8, P9) Trying to get along (P2) Getting angry with the disabled sibling (P2) Getting help from the family (P3, P5, P6) Going to places to get away from the situation (P3) Solution-oriented approach (P4, P9) Crying (P7)

For example, the issue of weight. Drugs make my brother gain weight. He can't walk for a long time; his feet hurt, his back hurts. People do not understand the situation. They make an expression like "wow he's too overweight, why did you let him eat this much?" They don't understand the situation. (P7)

Relatives and neighbours love him so much; they take care of him, my cousins come around and take care of him. (P9)

Emotions about Having a Disabled Sibling

The main theme of participants' emotions about having a disabled sibling is expressed under the five sub-themes of "sadness" (P1, P2, P3, P6, P10), "anger" (P2, P5, P8), "embarrassment" (P2), "love" (P3, P6, P8, P9, P10), "increased sense of responsibility" (P3, P4, P5, P6), "dissociation" (P4)". Participants' sample expressions are as follows;

It's particularly a fine line after becoming a mother. One understands what motherhood is like and what it feels like to be the mother of an individual with a disability. It's as if one becomes more sensitive with the hardship. (P1)

For example, when we were little, my sibling would get stubborn if we were to go somewhere and would refuse to leave the house. I would get embarrassed when I was younger. (P2)

It's a good thing. I love my brother, of course, we take care of his needs often. (P9)

I think it's a situation that dissociates us. Either my mother or my father stay with brother. For example when there's a wedding, one of us stays home with my brother, one of us makes a sacrifice (P4)

Way of Showing Love to the Disabled Sibling

The main theme of participants' way of showing love to the disabled sibling is expressed under the four sub-themes of "hugging" (P1, P2, P3), "sparing some time" (P1, P3), "caring about the sibling's wishes" (P1, P3, P4), "loving" (P4, P5, P6, P7, P8, P9, P10)". Participants' sample expressions are as follows;

We usually hug. We play together. We play games with my sibling, and we hug. We have a physical contact. We express our emotional bond by hugging each other. (P1)

We used to dance a lot, my sister has an ear for music, and she can also drum on things well, so the thing we love the most, and that makes us happy is hugging while we are dancing. We go shopping with my sister. I try on clothes; when I hold clothes in front of her, she feels very happy, she hugs me tightly, those are the best moments for me. We usually express our love by hugging each other. (P3)

I love my sibling very much. (P8)

Having Difficulties in Family Processes

The main theme of the participants' opinions about having difficulties in family processes is expressed under the eight sub-themes of "limited participation in social activities as a family" (P1, P2, P4, P6, P9), "requiring sharing of responsibilities" (P1, P3, P4), "difficulty controlling the compulsive behaviour of the disabled person" (P2, P3, P5, P7, P9), "situation that causes family conflicts" (P2), "a situation that wears out the caregiver" (P2, P3, P5, P6, P8, P10), "setting their needs aside because the priority is given to the disabled sibling" (P3), "having difficulty due to people around excluding the disabled sibling" (P5), "situation that limits one's own life" (P8). Participants' sample expressions are as follows;

We have a difficult time if there's an event, or if we are having guests over or if there's a wedding, feast day, service or any other occasion. Somebody needs to take care of my sibling. We can not adapt everywhere. (P1)

You grow up with a child who has not grown up since the age of six, and this affects your life both positively and negatively... the negative side is that you don't get to experience your childhood much, you grow up a little too early. (P3)

We have difficulties due to the reactions we receive from other people. There's nothing to be done, unconscious people are everywhere. (P5)

When I am in my room studying, my sister knocks on the door, she comes inside and wants to sit with me as I am studying. This process has been a little difficult. (P8)

Having Difficulty Explaining the Situation to the People Around

The main theme of participants' thoughts about having difficulty explaining the situation to the people around is expressed under the three sub-themes of "a situation that is more difficult when one is young and easier as one gets older" (P1), "having difficulty in expressing opinions when someone asks about the situation" (P1, P2, P3, P7, P8, P9, P10), "not wanting to share" (P4, P5, P6). Participants' sample expressions are as follows;

I might have had a hard time in childhood because I was not informed about the subject, and I didn't know about the extent of my sibling's disease. The difficulty I experienced was due to lack of knowledge, but that's not the case now. (P1)

We don't feel the need to explain much . There is no need. There are many people who are uninformed and who speak ignorantly. (P6)

Negative Situations with the Sibling

The main theme of the participants' opinions about negative situations with the sibling is expressed under the three themes of "inability to control compulsive behaviour" (P1, P2, P3, P4, P5, P6, P8, P9, P10), "not being able to spend enough time with the mother (P3)", "having difficulty in communication" (P7). Participants' sample expressions are as follows;

Sometimes I cannot foresee my siblings' reactions. He stresses and gets anxious. He may throw whatever he grabs, my sister may have been exposed to violence, he sometimes causes a mess in the house. (P5)

We have never experienced going anywhere as mother and daughter; we would always have to drop my sibling off somewhere; it was not very easy for us. Either I would take care of my brother, my mother would go out, or she would go take care of my brother, and I would go out. (P3)

Activities Done in the Face of Difficulties

The main theme of the participants' opinions about the activities done in the face of difficulties is expressed under the seven sub-themes of "sharing responsibility" (P1, P5, P8, P9), "trying to get along" (P2), "getting angry with the disabled sibling" (P2), "getting help from the family" (P3, P5, P6), "going to places to get away from the situation" (P3), "solution-oriented approach" (P4, P9), "crying" (P7). Participants' sample expressions are as follows;

Sometimes someone needs to act selflessly; we share the responsibility. (P1)

We try to give her something she likes, we try to get along. She listens to my advice because she seems to be a little afraid of me. (P2)

The person we get the most support from is my grandmother, both physically and psychologically. We trustingly drop my sibling there. Aside from her, there is also my aunt and my cousins. (P3)

We are solution-oriented, we always prioritise my sibling. (P4)

There needs to be a discharge by crying. (P7)

We asked participants about the activities they do with their disabled sibling and among the activities were “playing games” (P1, P9), “colouring” (P1), “reading a book” (P1), “watching television” (P2, P4), “limited sharing” (P2, P8), “going to places” (P3, P5, P7, P9, P10), “listening to music” (P4, P5, P6), “trying to teach something” (P4), “participating in the care of their sibling (P10)”.

We asked the participants a metaphor question asking them to liken having a disabled sibling to something; they described it as “something both sweet and sour” (P1), “The patience stone” (P2), “An abstract painting” (P3), “a book” (P4), “a baby” (P5), “The relationship between the mother and a child” (P6), “Heaven” (P7), “The relationship between the teacher and a student” (P8), “an angel” (P9), “a kangaroo” (P10). We presented the metaphors of the participants in Figure 1.

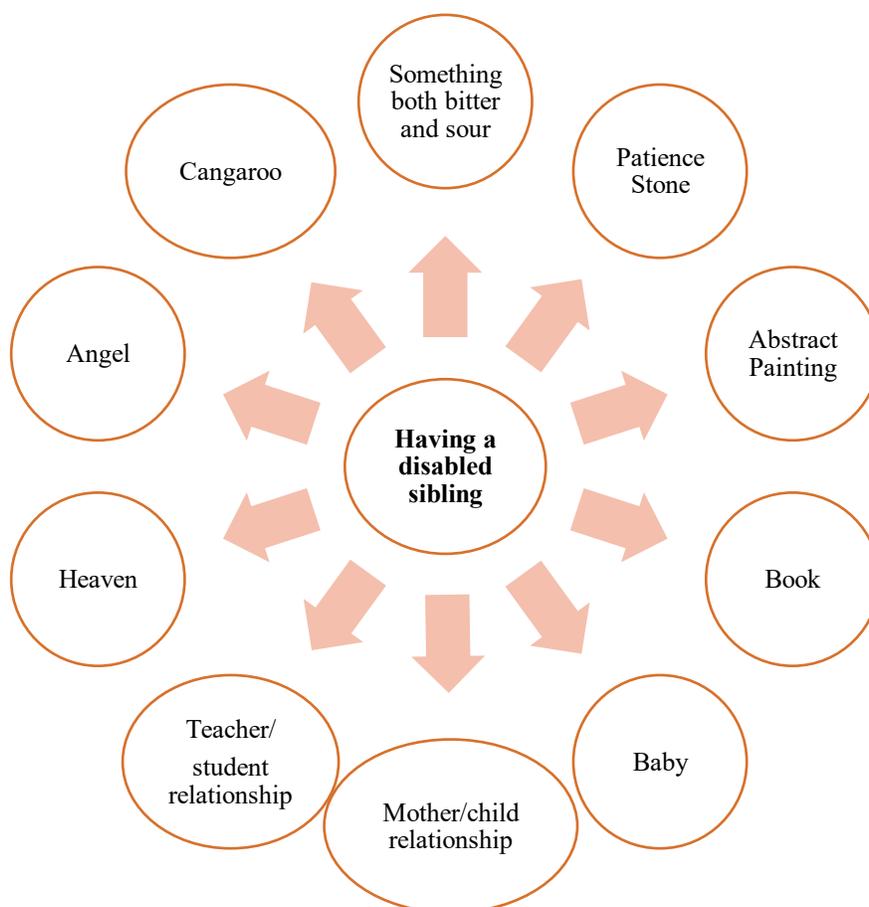


Figure 1. Metaphors

Discussion

In this study conducted in a qualitative research design, we evaluated the perceptions of individuals with an intellectually disabled sibling about having an intellectually disabled sibling, their lives and how they cope with the difficulties and obtained important findings. There are studies in the literature that suggest that the presence of an intellectually disabled child in the family can be a source of stress for the family, it may affect the relationship between siblings, healthy siblings may show negative emotions and behavioural reactions such as anger and jealousy because they think they receive less attention in the family (Van Riper, 2000; Luijkx, van der Putten & Vlaskamp, 2016; Jefferson, 2007), there are also studies suggesting that the healthy sibling's burden of having to take care of their disabled sibling is intense. In addition, the literature states that the presence of a disabled child in the family provides an opportunity for the development of positive emotions for family members, gives children positive emotions such as maturity trust and compassion and creates a positive communication environment in the family (Meyer & Vadasy, 2003). A striking finding of the study is that having a disabled sibling is challenging for healthy siblings; it differentiates their lives and gives them experience. This finding supports the finding in the literature that having a disabled child in the family contributes positively to family members' development, especially the healthy sibling's.

The literature states that the feelings of individuals with a disabled sibling towards their disabled sibling are anger, jealousy, guilt, sadness, shame, and distress, fear, anxiety, rejection (Aksoy & Yıldırım Berçin, 2008). Individuals with disabled siblings are psychologically affected by this situation (Luijkx, van der Putten & Vlaskamp, 2016; Marquis, Hayes & McGrail, 2019). Another study concluded that most individuals with a disabled sibling got upset when they first learned about their sibling's disability but didn't care much about it after a while and felt happy for having a sibling (Gözün Kahraman & Karadayı, 2015). In this research, during the evaluation of emotions about having a disabled sibling, participants stated that they felt the emotions of love, sadness and responsibility towards their sibling.

Studies state that most individuals with a disabled sibling state that they undertake different roles in the care of the disabled sibling (Heller & Kramer, 2009; Gera, Martin & Zahra, 2020). Studies state that the most important difficulty individuals with a disabled sibling face are the behavioural problems of the disabled sibling (Gözün Kahraman & Karadayı, 2015). Marquis, McGrail & Hayes (2020) stated that the siblings of individuals with different types of disability have an impact on individuals' mental health. In addition, the attitude of the parents towards the disabled child affects the attitude of the healthy sibling towards their disabled sibling (Yüksel & Tanrıverdi, 2019). It is stated that the stress level of individuals with a disabled sibling also increases due to the increase in the difficulty in taking care of the disabled sibling and there is a decrease in their level of coping with stress (Bilal & Dağ, 2005). One of the difficulties individuals with disabled siblings face is communication problems. Although there are studies revealing that the level of communication between siblings affects the relationship between feelings (Moysen & Roeyers, 2011), there are also studies revealing that the communication skills of disabled sibling do not affect the level of sibling relationships (Smith, Ronski & Sevcik, 2013). In this study, participants stated that having a disabled sibling is a condition that wears out the caregiver most, they have difficulty in controlling the compulsive behaviours of the disabled individual and have difficulty in family processes due to limitations in participating in social activities as a family, and that negative situations experienced with the sibling are mostly due to inability to control compulsive behaviours, and that they don't have difficulty in explaining the situation when other people ask questions. Despite this, participants shared that they expressed their love by hugging their disabled sibling, sparing time for them, caring about their wishes and loving them. In this context, although the disability causes different communication problems among siblings, the relationship between siblings is positive.

Studies have revealed that individuals with a disabled sibling often spend time with their siblings (Yavuz & Coşkun, 2014; Luijkx, van der Putten & Vlaskamp, 2016; Gera, Martin & Zahra, 2020). Gera et al. (2020) stated that playing with the sibling, reading a book, helping out the disabled sibling are activities that are done together. This study revealed that participants spare time for the disabled sibling and care about their siblings' requests. Although the vast majority of participants stated that they do in-house activities

such as playing games, colouring, reading books, watching television; nearly half of the participants stated that they go to places with their intellectually disabled sibling. Despite these differences, individuals with a disabled sibling have common behaviours such as sparing time for their disabled sibling, caring about their wishes and doing the activities that their sibling wants.

Individuals with an intellectually disabled sibling may face many difficulties. Individuals may experience stress and use different coping methods, depending on the difficulties they encounter. There are differences in terms of family and social relations between individuals who have an intellectually disabled sibling and those who do not have an intellectually disabled sibling (Hayden, Hastings, Totsika & Langley, 2019). A study stated that individuals with an intellectually disabled sibling experience more psychopathological problems compared to their peers and have more problems in interpersonal relationships (Emerson & Giallo, 2014). One of the factors affecting the relationships between disabled and non-disabled siblings is the type of the disability (Hodapp & Urbano, 2007; Mandleco & Webb, 2015; Marquis, Hayes & McGrail, 2019). Individuals who perceive good marital relations of their parents and have a disabled sibling have more positive opinions about the disabled sibling and have a more positive relationship with the disabled sibling (Beyer, 2009). This study concluded that participants mostly showed the behaviours of sharing more responsibility, getting help from the family to cope with difficulties.

In Turkey, the national legal framework also acknowledges the role and needs of families with disabled members, though direct references to siblings are limited. The Law on Disabled Persons No. 5378 emphasizes the principle of protecting family unity and supporting the social participation of persons with disabilities (Law on Disabled Persons, 2005). Additionally, the Law on Social Services No. 2828 outlines the responsibility of the state in providing psychosocial and protective services to families with disabled individuals, which may indirectly benefit siblings (Law on Social Services, 1983). The inclusion of families in habilitation and rehabilitation planning is also mandated by law. Moreover, the responsibilities assigned to the Ministry of Family and Social Services by Presidential Decree No. 4 include promoting the well-being of both disabled persons and their families (Presidential Decree No. 4, 2018). These provisions can be interpreted as an acknowledgment of the psychosocial burden experienced by siblings and the need for family-centered support mechanisms. However, practical services specifically addressing the mental health, caregiving burden, and emotional resilience of siblings remain limited, highlighting a gap in policy implementation.

The metaphor question asked the participants to liken having a disabled sibling to something; the individuals expressed difficulty in expressing, they used complex and abstract expressions such as something both sweet and sour and an abstract painting. In addition, it is noteworthy that expressions such as the patience stone, which emphasise the aspect that requires patience, the relationship between the teacher and the student, which emphasise the learning aspect, kangaroo and the relationship between the mother and the child which emphasise the caring aspect. Considering that the participants responded by considering the dimensions of their relationship with their disabled siblings, the situations experienced by individuals are similar, their feelings and thoughts differ.

Conclusion and Recommendations

Having an intellectually disabled child in the family is a dynamic process that affects the whole family, especially other children in the family. It is a situation that needs to be managed. Individuals with an intellectually disabled sibling think that the condition of their intellectually disabled sibling is a difficult process, but they also accept it over time and have positive sibling relationships. The results obtained will guide health professionals in identifying and supporting the problems of children with disabled siblings. It is important to determine the needs of individuals with intellectually disabled siblings and take care of them. The services to be provided to intellectually disabled individuals should be planned in a way to include the disabled person, their siblings, parents, that is, all caregivers, and individuals should be supported psychosocially. It is recommended to increase the institutions where the care and treatment of disabled individuals will be provided, to carry out practices that will support the individual and their family in terms

of psychosocial support in these institutions, to conduct comparative studies in sibling relations in different disability.

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References

- Aksoy, A. B. & Berçin Yıldırım, G. (2008). A study of the relationships and acknowledgement of non-disabled children with disabled siblings. *Journal of Educational Sciences in Theory and Practice*, 8(3), 769-779.
- Atkin, K., & Tozer, R. (2014). Personalisation, family relationships and autism: Conceptualising the role of adult siblings. *Journal of Social Work*, 14(3), 225-242. <https://doi.org/10.1177/1468017313476453>
- Benson, P. R. & Karlof, K. L. (2008). Child, parent and family predictors of latter adjusment in sibling of children with autism. *Research in Autism Spectrum Disorders*, 2(4), 583-600. <https://doi.org/10.1016/j.rasd.2007.12.002>
- Beyer, J. F. (2009). Autism spectrum disorders and sibling relationships: Research and strategies. *Education and Training in Developmental Disabilities*, 44(4), 444-452. <https://www.jstor.org/stable/24234254>
- Bilal, E. & Dağ, I. (2005). The comparison of stress, locus of control and coping styles in mothers of children with mild mental diability and in mothers of typically developing children. *Turk. J. Child. Adolesc. Ment. Health*. 12(2), 56–68.
- Burke, M.M., Taylor, J.L., Urbano, R. & Hodapp, R.M. (2012). Predictors of Future Caregiving by Adult Siblings of Individuals With Intellectual and Developmental Disabilities. *Journal of Intellectual & Developmental Disability*, 117(1):33-47. <https://doi.org/10.1352/1944-7558-117.1.33>
- Coyle, C.E., Kramer, J. & Mutchler, J.E. (2014). Aging together: Sibling carers of adults with intellectual and developmental disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 11(4),302-312. <https://doi.org/doi.org/10.1111/jppi.12094>
- Creswell, J. W. (2018). *Nitel araştırma yöntemleri: Beş yaklaşıma göre nitel araştırma ve araştırma deseni* (M. Bütün ve S. B. Demir, Çev., Yay. haz.). Siyasal Kitapevi.
- Emerson, E. & Giallo, R. (2014). The wellbeing of siblings of children with disabilities. *Research in Developmental Disabilities*, 35(9), 2085-2092, <https://doi.org/10.1016/j.ridd.2014.05.001>
- Er, M. (2006). Child, illness, parents and siblings. *Journal of Child Health and Diseases*, 49, 155-168.
- Erden, G. & Akçakın, M. (2001). Patterns of behavioural problems and personality traits of children with autism and their siblings. *Journal of Child Health and Diseases*, 8(3), 145-155.
- Gera J. V., Martin G. M. & Zahra A. J. C. (2020). An insight into the lives of young siblings of disabled children in Malta. *Disability & Society*, <https://doi.org/10.1080/09687599.2020.1712188>
- Gözün Kahraman, Ö, & Karadayı, N. (2015). Views of children with a disabled sibling regarding their experiences with their disabled sibling. *Journal of Hacettepe University Faculty of Health Sciences*, 1, 391-408.
- Hayden, N. K., Hastings, R. P., Totsika, V. & Langley, E. (2019). A population-based study of the behavioral and emotional adjustment of older siblings of children with and without intellectual disability. *Journal of Abnormal Child Psychology*, 47(8), 1409-1419. <https://doi.org/10.1007/s10802-018-00510-5>
- Heller, T. & Kramer, J. (2009). Involvement of Adult Siblings of Persons With Developmental Disabilities in Future Planning. *Journal of Intellectual & Developmental Disability*, 47(3),208-219. <https://doi.org/10.1352/1934-9556-47.3.208>
- Hodapp, R. M., & Urbano, R.C. (2007). Adult siblings of individuals with down syndrome versus with autism: Findings from a large-scale US survey." *Journal of Intellectual Disability Research*. 51(12), 1018–1029. <https://doi.org/10.1111/j.1365-2788.2007.00994.x>
- İçmeli, C. Özçetin, A. Ataoğlu, B. B. & Ankaralı, H. (2015). Characteristics of attention deficit and hyperactivity disorder in children and adolescents having mental retardation. *Journal of Düzce University Health Sciences Institute*, 5(2), 12-18.

- İnanç, B., Ceyhun, A. T., & Özdemir, H. D. (2024). Özel gereksinimli kardeşe sahip olan bireylerde duygusal yük, psikolojik sağlamlık ve depresyon düzeylerinin incelenmesi. *Bayburt Eğitim Fakültesi Dergisi*, 20(45), 339-362.
- Jefferson, M. (2007). *Link ages between family cohesion and sibling relationships in families raising a child with a disability* [Master's Thesis]. Brigham Young University, Department of Counselling Psychology and Special Education. <https://scholarsarchive.byu.edu/etd/419>
- Kahraman, Ö., & Karadayı, N. (2015). Engelli kardeşe sahip olan çocukların engelli kardeşleriyle deneyimlerine ilişkin görüşleri. *Hacettepe University Faculty of Health Sciences Journal*, 1(2), 390-408.
- Kuru-Akçeken, S. (2024). *Özel gereksinimli çocuğu olan babaların depresyon düzeyleri ve baba katılım düzeyleri arasındaki ilişkinin incelenmesi* (Tez No. 857821) [Master's Thesis]. İstanbul Gelişim University. <https://hdl.handle.net/11363/9183>
- Law on Disabled Persons, No. 5378. (2005, July 7). Official Gazette (No. 25868). Retrieved from <https://www.mevzuat.gov.tr/mevzuat?MevzuatNo=5378&MevzuatTur=1&MevzuatTertip=5>
- Law on Social Services, No. 2828. (1983, May 24). Official Gazette (No. 18059). Retrieved from <https://www.mevzuat.gov.tr/mevzuat?MevzuatNo=2828&MevzuatTur=1&MevzuatTertip=5>
- Luijckx, J., van der Putten, A. A. J., & Vlaskamp, C. (2016). "I love my sister, but sometimes I don't": A qualitative study into the experiences of siblings of a child with profound intellectual and multiple disabilities. *Journal of Intellectual & Developmental Disability*, 41(4), 279–288. <https://doi.org/10.3109/13668250.2016.1224333>
- Mandleco, B., & Webb, A. E. M. (2015). Sibling perceptions of living with a young person with down syndrome or autism spectrum disorder: An integrated review. *Journal for Specialists in Pediatric Nursing* 20(3),138–156. <https://doi.org/10.1111/jspn.12117>
- Marquis, S., Hayes, M. V. & McGrail, K. (2019). Factors that may affect the health of siblings of children who have an intellectual/developmental disability. *Journal of Policy and Practice in Intellectual Disabilities*, 16(4), 273-286. <https://doi.org/10.1111/jppi.12309>
- Marquis S., McGrail, K. & Hayes, M. V. (2020). Using administrative data to examine variables affecting the mental health of siblings of children who have a developmental disability. *Research in Developmental Disabilities*, 96, 103516. <https://doi.org/10.1016/j.ridd.2019.103516>
- Meyer, D. J. & Vadasy, P. F. (2003). *Sibshops: Workshops for siblings of children with special needs* (5th Edition). Paul H. Brookes Publishing Co.
- Moyson, T. & Roeyers, H. (2011). The quality of life of Siblings of children with autism spectrum disorder. *Exceptional Children* 78, 41–55. <https://doi.org/10.1177/001440291107800103>
- Mulroy, S., Robertson, L., Aiberti, K., Leonard, H., & Bower, C. (2008). The impact of having a sibling with an intellectual disability: Parental perspectives in two disorders. *Journal of Intellectual Disability Research*, 52,216-229. <https://doi.org/10.1111/j.1365-2788.2007.01005.x>
- Presidential Decree No. 4 on Organization of Ministries. (2018, July 10). Official Gazette (No. 30474, 2nd repeated). Retrieved from <https://www.resmigazete.gov.tr/eskiler/2018/07/20180710-1-1.pdf>
- Smith, A. L., Ronski, M. & Sevcik, R.A. (2013). Examining the role of communication on sibling relationship quality and interaction for sibling pairs with and without a developmental disability. *American Journal on Intellectual and Developmental Disabilities* 118(5), 394–409. <https://doi.org/10.1352/1944-7558-118.5.394>
- Türkoğlu, Y. (2023). *Zihinsel yetersizliği olan çocukların ebeveynlerinde bakım verme yükü ve ilişkili etmenlerin belirlenmesi* [Master's Thesis]. Pamukkale University.
- Üstdağ, E. L., & Bumin, G. (2014). Investigation the effects of group activities on scial participation and sibling relationship applied to disabled children and their sibling: a pilot study. *Journal of Occupational Therapy and Rehabilitation*, 2(3), 141-147.
- Van Riper, M. (2000). Family variables associated with well-being in siblings of children with down syndrome. *Journal of Family Nursing*, 6(3), 267-286. <https://doi.org/10.1177/107484070000600305>
- Yavuz, M., & Coşkun, İ. (2014). Recreation of normal developing children and their mentally disabled siblings. *Turkish Studies*. 9(8),295-313. <https://doi.org/10.7827/TurkishStudies.7215>
- Yıldırım A., & Şimşek H. (2016). *Sosyal bilimlerde nitel araştırma yöntemleri*. (10th Ed.). Seçkin Yayıncılık.
- Yüksel, H., & Tanrıverdi, A. (2019). Social problems and coping ways of families of children with special needs. *Ankara University Faculty of Educational Sciences Journal of Special Education*, 20(3), 535-559. <https://doi.org/10.21565/ozelegitimdergisi.493089>