

Living in the shadow of autism: the lived experience of having a sibling with autism

Saba Poolaie¹, Farzaneh Mokhtary^{1✉}, Akram Sanagoo², Leila Jouybari²

ABSTRACT

OBJECTIVE: This study was conducted to illuminate lived experiences of individuals having a sibling with autism.

METHODS: This qualitative case study was conducted to explore the lived experiences of a 20-year-old girl living with a 17-year-old brother with autism. Data was collected through interactive, semi-structured interviews. Two 60-minute interactive interview sessions were conducted, recorded and transcribed. Rigor in the study was ensured through prolonged engagement and researcher familiarity with the data. Feedback from the participant and nursing faculty members was sought for revisions. Data was analyzed following Van Manen's six-step phenomenological approach. OneNote 2016 software was utilized to record, organize, and extract interview data and codes.

RESULTS: The data analysis resulted in the identification of three main themes: "hiding autism," "I never had a childhood", and "motherly sister". These themes were further divided into seven sub-themes, including "withdrawing from friends", "anguish over non-normative behaviors", "avoiding others' questions", "you have to take care of him", "struggling with academics," "an embrace full of positive energy," and "never leaving him alone".

CONCLUSION: This study highlights the complex experiences of siblings living with a sibling diagnosed with autism, revealing both challenges and moments of resilience and love. The findings emphasize the importance of tailored support and increased awareness for promoting the well-being of siblings in similar situations. However, its single-participant limitation calls for broader, diverse studies to understand these experiences across various cultural, economic, and social contexts.

KEYWORDS: Autism Spectrum Disorder (MeSH), Autistic Disorder (MeSH), Lived Experience (Non-MeSH), Phenomenology (Non-MeSH).

THIS ARTICLE MAY BE CITED AS: Poolaie S, Mokhtary F, Sanagoo A, Jouybari L. Living in the shadow of autism: the lived experience of having a sibling with autism. *Khyber Med Univ J* 2024;16(1):72-6. <https://doi.org/10.35845/kmuj.2024.23428>

1: Student Research Committee, Golestan University of Medical Sciences, Gorgan, Iran.

2: Faculty of Nursing and Midwifery, Golestan University of Medical Sciences, Gorgan, Iran.

Email ✉: mokhtary.farzaneh882@gmail.com

Date Submitted: July 29, 2023

Date Revised: March 15, 2024

Date Accepted: March 16, 2024

disabilities. However, other researchers have shown that at least some siblings of children with ASD adapt well and even experience potential positive outcomes, including better emotional and behavioral adaptation, increased social competence, and more positive self-perception compared to siblings of children with other disabilities or those who have no disabilities.⁵

The presence of autism has different effects on the quality of life for non-autistic siblings. Non-autistic siblings of individuals with autism experience reduced psychological well-being, perceived lower social support, increased aggression and conflict tendencies, and higher levels of anxiety and stress, which impact their quality of life.⁶ We couldn't find a study that specifically examines the experience of a sibling with autism in Iran's cultural context. This case study aimed to explore the experiences of a girl who has lived with her younger brother, diagnosed with autism, for a span of 17 years.

METHODS

This qualitative case study aimed to explore the experiences of living with a sibling with autism. The participant was a 20-year-old girl who has lived with her 17-year-old brother with autism since childhood, alongside their parents. Two 60-minute interactive interview sessions were conducted. The interview was conducted in a calm and confidential environment, chosen by the participant with her full consent. The main researcher, a doctoral nursing

INTRODUCTION

Autism is a developmental disorder that affects how a person communicates, interacts with others, and processes sensory information. It is a spectrum disorder, meaning that symptoms and severity can vary greatly between individuals. Autism impacts all aspects of a child's life, including daily activities, home, school, and interactions with family members and others.¹ Having a family member with autism spectrum disorder (ASD) has a profound impact on the entire family.² Parents and siblings of children with autism often experience elevated levels of anxiety, stress, isolation, and

uncertainty.³ Sibling interactions are an important and powerful factor in a child's development. Their longitudinal interactions and ongoing relationship have a significant impact on cognitive, social, and emotional growth. The quality of sibling relationships is a strong predictor of mental health outcomes.⁴ Research examining the adaptation and relationships of typically developing siblings and siblings with autism supports the hypothesis that growing up with a sibling with ASD may put typically developing siblings at a higher risk for emotional and behavioral difficulties compared to siblings of children with other disabilities or children without

student, conducted the interview under the supervision of a qualitative research expert. The interviews began with a brief introduction, followed by open-ended questions such as "What is it like living with a sibling with autism? Tell me about a day in your life with your brother. How do you spend time together?" and exploratory questions such as "Why? How? Can you give an example?" The aim of this study was to answer the question of what it is like to live with a sibling with autism. To ensure the study's rigor, prolonged engagement, and sufficient researcher familiarity with the data, feedback was obtained from the participant, and revisions were made based on input from nursing faculty members. The interviews were recorded, transcribed, and analyzed using the Van Manen phenomenological approach in six steps. OneNote 2016 software was utilized to record, organize, and extract interview data and codes.

At the beginning of this study, the objectives and nature of the research were explained to the participant, and informed consent was obtained for observation and audio recording. Additionally, necessary commitments were made to maintain confidentiality and allow withdrawal of participation at any stage of the research.

The study obtained ethical approval from the Research Ethics Committee of Golestan University of Medical Sciences under the code IR.GOUMS.REC.1402.078. Stringent adherence to ethical principles, including confidentiality, was ensured throughout the study.

RESULTS

From the analysis of the interviews, 35 meaningful units were extracted and grouped into three main themes: "Hiding Autism," "I Never Had a Childhood," and "Motherly Sister." These themes were further divided into seven sub-themes, including "Withdrawing from Friends," "Anguish over Non-Normative Behaviors," "Avoiding Others' Questions," "You Have to Take Care of Him," "Struggling with Academics," "An Embrace Full of Positive Energy," and "Never Leaving Him Alone." The findings are delineated

in Table I, categorized according to the primary themes.

Hiding Autism

The participant has tried to hide their brother's condition and circumstances for various reasons throughout their life. Sometimes, the reason for this hiding is fear of their brother being mocked, and other times it is due to being tired of answering others' repeated questions. In this regard, the participant's statements were as follows:

Withdrawing From Friends

To hide her brother's autism from others, it was necessary for her to distance herself from her friends, and this repeated and daily experience has been distressing and unpleasant.

"One of the most challenging aspects for me was when people asked about my siblings. I would respond that I have one younger brother, but when they asked about his grade level, I found it difficult to answer truthfully. Instead, I would hesitate and say that he was in a higher grade, or I would make up a false reason for my visit. I avoided spending time with my friends because my mother worked shifts, and even when my father was present, I needed to stay home to care for Hussain."

Anguish Over Non-Normative Behaviors

Non-normative behaviors can cause significant distress for individuals and their loved ones. The following quote highlights the anguish that can arise from navigating these behaviors.

"When we go to parties, I have to be very careful about what he does and doesn't do. He might go into the kitchen and check if they have yogurt in the fridge or not. He takes the artificial flower stems and separates them, spinning the flowers around. Some people say it's not a big deal, let him be comfortable. But in new places that we take Hussain for the first time, we have to be more cautious."

Insufficient awareness and understanding of autism in society has been observed to elicit frustration and anxiety in individuals who are repeatedly questioned about the condition. This often results in a tendency to conceal the diagnosis of loved ones, as the burden of having to provide explanations can be

emotionally taxing.

"Many people in society don't know what autism is! It frustrates me when they ask what autism means, my nerves get overwhelmed. That's why I didn't want to tell anyone about Hussain. I didn't have the patience for explanations afterwards. For example, they would ask, 'What does autism mean? What is it like? Can he use the bathroom?' How long do these kids live? It really bothered my mom. I saw tears in her eyes, these questions shouldn't be asked. We get really upset by these explanations."

I Never Had a Childhood

The data indicates that the participant, due to being older and also the specific conditions of their brother, faced challenges and different experiences from their peers at a young age. They witnessed the pain and distress of their parents and the unconventional behaviors of their brother.

"One time, my aunt was talking to her daughter in a childish tone, and considering that there is a three-year age difference between me and my cousin, I asked my aunt why she talks to Ela like that. Shouldn't you talk to her like an adult at this age? She said, 'No, she's still a child!' I said, 'But when I was her age, my parents didn't talk to me like that.' Suddenly, my aunt turned back and said, 'You never had a childhood.' For a moment, I thought to myself, 'Yes, I really didn't have a childhood.' From certain points onwards, my parents couldn't and shouldn't focus on me; they had to pay attention to Hussain."

You Have to Take Care of Him

The participant described numerous situations in which she was annoyed by her younger brother, who caused damage to her school supplies and caused her distress. Despite the participant's concerns, her parents dismissed the brother's behavior.

"The school period brings my books and pencils, he opens their tubes and breaks their brains. My notebooks were standing, I cried over these things too, my parents said that he's just a child, he doesn't understand, you should take care of yourself, you should understand him."

Struggling with Academics

The participant encountered

considerable academic challenges during this period. Despite diligent studying, she experienced increased stress due to her younger sibling, Hussain, who frequently arrived home before her and disrupted the household.

"I studied very hard during that time, sometimes when I came home from school, Hussain would come home before me and mess up the house. I had so much stress from the college entrance exam that it upset my stomach; I wouldn't eat anything at school from 8 am to 2 pm, then I would come home and start cleaning. I was so tired that I would sleep in the same school uniform. When my mother arrived, she would say, 'Get up, get up and study.'"

Motherly Sister

The participant's scattered conversations reveal her ongoing concern and self-sacrifice for her brother, highlighting her strong sense of responsibility towards him.

An Embrace Full of Positive Energy

Alongside all the difficulties and challenges of life with her brother, the participant mentions her enthusiasm and love for her brother. She describes an embrace full of positive energy, saying,

"I hug and kiss him for no reason a hundred times a day. And he hugs me back, we really love each other."

Never Leaving Him Alone

The strong bond and attachment between siblings, particularly when one of them has autism is expressed in below. The participant indicates that leaving her sibling and building a separate life is unimaginable, highlighting the depth of their connection.

"Occasionally, my mother reminds me that someday I will depart from this household and establish my own life. However, I find it difficult to come to terms with this idea because I cannot fathom the thought of leaving and not having Hussain by my side."

DISCUSSION

This study highlights the main themes and sub-themes that emerged from the

data analysis, providing insight into the lived experiences of having a sibling with autism. One of the prominent concepts observed in this research was the concealment of the illness, which has also been identified in Benedix's study. Most siblings did not invite friends over when their autistic sibling was present, as they perceived their sibling's abnormal, frightening, aggressive, and destructive behaviors to be a deterrent. Additionally, the autistic child's demands on parental attention and time left little room for siblings to pursue their own interests or socialize with friends.⁷ As a result, some siblings did not reveal to others at school that they had a sibling with autism. To address this, siblings need more information about autism not only to enhance their understanding but also to explain to others more easily why their sibling behaves differently.⁸ The participant in this study referred to the theme of "I never had a childhood." In her discussions, she attributed this issue to her parents' distress and the need for more attention from them

towards her sibling. In families with an autistic child, the parents' disproportionate attention towards the child with autism often leaves less attention for their other children.⁹ Although many siblings have understood the needs of their autistic sibling, they have also experienced feeling neglected in meeting their own needs.¹⁰ Some have taken on the role of supporting their parents and helping alleviate the pressure on them. For example, one adolescent mentioned, "When I think my parents need rest, I go and try to calm them down".⁷ Another main theme identified by Morris in his study was "stolen childhood," which focuses on the participants' perception of their childhood spent taking care of their sibling. Some participants recall forming a close relationship with their sibling with ASD and continuing it into adulthood. However, it is worth noting that this case is not necessarily negative.¹¹ Compassion, empathy, and unwavering concern towards a sibling with autism were prominent themes

Table I: Main themes and sub-themes in the lived experience of siblings with autism

Meaning units	Sub-themes	Main themes
Staying at home	Withdrawing from friends	Hiding Autism
Not inviting friends to her house		
Breaking sharp objects	Anguish over non-normative behaviors	
Turning things in hand		
Anger from questions	Avoiding others' questions	
Lack of awareness about autism		
You are guilty	You have to take care of him	I never had a childhood
Lock in closets		
going to the pension	Struggling with academics	
Breaking pencils, Hide the books		
Prepare food	Constant worry	Motherly sister
Caring for the harm of others		
A motivation to study	An embrace full of positive energy	
Having fun with each other		
being together	Never leaving him alone	
Understanding brother		

that emerged from the study's participant. This highlights the "motherly" role that siblings often adopt in caring for their autistic brother or sister. In similar studies, many siblings expressed a sense of duty to protect their sibling from engaging in risky behaviors and prevent them from causing harm to themselves or others. Some even took on the role of caregivers to relieve their parents of daily care responsibilities.^{12,13} As siblings grow older, research shows that their level of empathy and compassion towards the individual with autism increases, enabling them to better understand their sibling.¹⁴

According to a study, all adolescent siblings who were interviewed had positive opinions about their siblings with autism. They provided positive descriptions of their behavior, specific personality traits, and reported positive experiences and time spent together, emphasizing the positive impact that having a sibling with autism can have on their own characteristics as siblings.⁵ Eliza, a participant in a separate study, conveyed that she views autism as an inseparable aspect of her sister's identity. She expressed that she cannot imagine her sister as anything other than an individual with autism, and that this has become normal to her. Through this process of normalization, Eliza gained a deeper understanding of her sister and developed a genuine love for her, as described in the study.¹⁵

The study's findings suggest that the participant has had a range of experiences with their sibling with autism throughout their childhood and into adulthood. During childhood, these experiences may have been challenging, such as feeling excluded from social gatherings, struggling with academic studies, observing unusual and unconventional behaviors of their sibling, or being unintentionally blamed for incidents or mischief caused by their sibling. However, as they grew older and gained a better understanding of their sibling's condition, they became more involved with their family than ever before. They stood by their sibling as a constant supporter, alongside their parents, and demonstrated a motherly spirit by never leaving them alone. It is

important to note that this study solely relied on verbal interviews with participants and did not have the opportunity to observe the sibling relationship up close in the home and family environment, which is a limitation to the study.

CONCLUSION

This qualitative case study highlights the intricate experiences of living with a sibling diagnosed with autism. Themes such as "Hiding Autism," "I Never Had a Childhood," and "Motherly Sister" reveal the challenges and responsibilities siblings face, alongside moments of love and resilience. Greater awareness and tailored support are essential for promoting the well-being of siblings of individuals with autism. This study's limitation of a single participant emphasizes the need for future research with larger, diverse samples across various cultural, economic, and social contexts. Such studies are vital for gaining a comprehensive understanding of the experiences discussed.

ACKNOWLEDGMENT

The research team would like to express their sincere appreciation and gratitude to the family of the adolescent who gave permission to share their life story.

REFERENCES

1. Javadian SR, Kafi FS, Babaeian N, Sadati AK. The Coping Strategies to Autism Disorder among Mothers of Autistic Children: A Qualitative Study. *Iran J Rehabil Res Nurs* 2022; 8(3): 17-29. <https://doi.org/10.22034/IJRN.8.3.17>
2. Gómez LE, Morán ML, Alcedo MÁ, Arias VB, Verdugo MÁ. Addressing quality of life of children with autism spectrum disorder and intellectual disability. *Intellect Dev Disabil* 2020; 58(5): 393-408. <https://doi.org/10.1352/1934-9556-58.5.393>
3. Webster A, Feiler A, Webster V, Lovell C. Parental perspectives on early intensive intervention for children diagnosed with autistic spectrum disorder. *J Early Child Res* 2004; 2(1): 25-49. <https://doi.org/10.1177/1476718X0421002>
4. McHale SM, Updegraff KA, Whiteman SD. Sibling relationships and influences in childhood and adolescence. *J Marriage Fam* 2012; 74(5): 913-30. <https://doi.org/10.1111/j.1741-3737.2012.01011.x>
5. Petalas MA, Hastings RP, Nash S, Reilly D, Dowey A. The perceptions and experiences of adolescent siblings who have a brother with autism spectrum disorder. *J Intellect Dev Disabil* 2012; 37(4): 303-14. <https://doi.org/10.3109/13668250.2012.734603>
6. Quatrosi G, Genovese D, Amodio E, Tripi G. The quality of life among siblings of autistic individuals: a scoping review. *J Clin Med* 2023; 12(3): 735. <https://doi.org/10.3390/jcm12030735>
7. Benderix Y, Sivberg B. Siblings' experiences of having a brother or sister with autism and mental retardation: A case study of 14 siblings from five families. *J Pediatr Nurs* 2007; 22(5): 410-18. <https://doi.org/10.1016/j.pedn.2007.08.013>
8. Petalas MA, Hastings RP, Nash S, Dowey A, Reilly D. "I like that he always shows who he is": The perceptions and experiences of siblings with a brother with autism spectrum disorder. *Intl J Disabil Dev Educ* 2009; 56(4): 381-99. <https://doi.org/10.1080/10349120903306715>
9. Kocabiyik OO, Fazlioglu Y. Life stories of parents with autistic children. *J Educ Train Stud* 2018; 6(3): 26-37. <https://doi.org/10.11114/jets.v6i3.2920>
10. Leedham AT, Thompson AR, Freeth M. A thematic synthesis of siblings' lived experiences of autism: Distress, responsibilities, compassion and connection. *Res Dev Disabil* 2020; 97: 103547. <https://doi.org/10.1016/j.ridd.2019.103547>

103547

11. Morris V, Hendry G, Wilson C, Gillespie-Smith K, Ballantyne C. A comparison of attitudes and knowledge towards autism based on adult sibling experiences. *J Adult Dev* 2023; 2:1-13. <https://doi.org/10.1007/s10804-023-09454-7>

12. Seligman M, Darling RB. Ordinary families, special children: A systems approach to childhood disability. 3rd

edition. The Guilford Press, New York, USA. ISBN: 978-1606233177

13. Tomeny TS, Barry TD, Fair EC, Riley R. Parentification of adult siblings of individuals with autism spectrum disorder. *J Child Fam Stud* 2017; 26:1056-67. <https://doi.org/10.3109/13668250.2016.1248376>

14. Mandileco B, Webb AE. Sibling perceptions of living with a young person with Down syndrome or

autism spectrum disorder: An integrated review. *J Spec Pediatr Nurs* 2015;20(3):138-56. <https://doi.org/10.1111/jspn.12117>

15. Pavlopoulou G, Dimitriou D. In their own words, in their own photos: Adolescent females' siblinghood experiences, needs and perspectives growing up with a preverbal autistic brother or sister. *Res Dev Disabil* 2020;119:103556. <https://doi.org/10.1016/j.ridd.2019.103556>

AUTHORS' CONTRIBUTION

Following authors have made substantial contributions to the manuscript as under:

SP: Study design, acquisition of data, drafting the manuscript, approval of the final version to be published

FM: Conception and study design, acquisition of data, drafting the manuscript, approval of the final version to be published

AS & LJ: Analysis and interpretation of data, critical review, approval of the final version to be published

Authors agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

CONFLICT OF INTEREST

Authors declared no conflict of interest, whether financial or otherwise, that could influence the integrity, objectivity, or validity of their research work.

GRANT SUPPORT AND FINANCIAL DISCLOSURE

Authors declared no specific grant for this research from any funding agency in the public, commercial or non-profit sectors

DATA SHARING STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request



This is an Open Access article distributed under the terms of the Creative Commons Attribution-Non Commercial 4.0 Generic License.

KMUJ web address: www.kmuj.kmu.edu.pk

Email address: kmuj@kmu.edu.pk