


# Lived Experiences of Siblings of Individuals with Autism Spectrum Disorder in India: An Interpretative Phenomenological Analysis

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## ABSTRACT

**Background:** Autism spectrum disorder (ASD) can impact the individual and their families. The impact on siblings is unique because they evolve from being another child in the family to a future adult who can be a potential resource to the family in supporting a member with ASD. Since the quality of care and support can be affected by the lived experiences of the carer and there are not many studies on siblings, this study examined the lived experiences of siblings of individuals with ASD.

**Methods:** Fourteen siblings of individuals with ASD, aged 15–36 years, were recruited from a tertiary hospital, schools, and private institutes. A semistructured interview schedule was used to explore the lived experiences. Interpretative phenomenological analysis (IPA) was used to identify the themes.

**Results:** The themes based on IPA indicated that the siblings have very basic concerns like understanding the condition and complex issues such as coping, preparing for current and future roles, personal needs and expectations, need for a support system, and positive aspects of the sibling

relationship. Nonetheless, the siblings minimized reporting their difficulties and focused more on the needs of the sibling with ASD.

**Conclusion:** Siblings have diverse lived experiences, with a small element of positive experiences. Appropriate supports are needed to address the complexities of the lived experiences.

**Keywords:** ASD, siblings, lived experiences, interpretative phenomenological analysis

**Key Messages:** Siblings have specific needs and concerns related to understanding ASD, coping with challenging experiences, roles and responsibilities; issues with the support system; and specific needs and expectations. They also have a positive sibling relationship in the context of ASD. These findings highlight the need to involve siblings in family support programs and extend appropriate individualized support.

Autism spectrum disorder (ASD) is a developmental condition associated with difficulties in social interaction and communication and repetitive or stereotyped behaviours.<sup>1</sup>

Given that ASD lasts lifelong and has specific implications for caregiving, it is important to understand the needs and experiences of all the family members. However, much of the literature has focused only on the parents.<sup>2</sup> For siblings, the transition from being a child who needs support from parents to being the “normal child” who is expected to support the parents in providing care for a family member with ASD can be very complex. In this context, understanding the lived experiences of the siblings is crucial to offer appropriate support.

Family theories that are modified to consider individuals with disabilities have been proposed. The transactional model of development<sup>3</sup> theorizes that disability in a child can increase demands on parents, which in turn can lead to less attention toward the needs of the sibling. Bronfenbrenner’s<sup>4</sup> ecological model shows how external systems can influence the actions of each member, which, in turn, can influence other family members. For example, stigma toward the individual with the disability

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can influence the coping of the parents, which, in turn, might influence sibling's interactions with the individual. These factors can result in unique needs that should be considered at the time of family interventions.

An idiographic approach is useful to understand the lived experiences of family members. Most previous studies employed interpretative phenomenological analysis (IPA), which presents the subjective experience and meaning-making process of research participants<sup>5,6</sup> while also not ignoring the researcher's interpretations of the phenomenon under study.<sup>7</sup> Several IPA-based studies indicate that mixed experiences are ubiquitous but the positive reinterpretation of the experiences is seen more among the older siblings.<sup>8,9</sup> ASD-specific factors such as challenging behaviors, interpersonal issues<sup>10,11</sup> and family dynamics create a tension between relational closeness and distancing, which in turn can increase negative experiences.<sup>12</sup> However, once siblings start reinterpreting the situation, they will be more supportive of the sibling with ASD and experience more life satisfaction.<sup>13</sup> Among the qualitative methods, IPA allows the researcher to explore and analyze the lived experiences without discounting the role of the researchers' interpretations.<sup>6</sup> Therefore, IPA seems to be the most suitable method to study the lived experiences and the meaning-making processes involved in these experiences.

It is important to understand lived experiences of the siblings in the Indian context as siblings are considered to be the future caregivers because formal support systems are not always adequate and stigma toward ASD is widely prevalent in the communities.<sup>14</sup> Moreover, published studies on the experiences of siblings of individuals with ASD are few internationally and are nil from India. In this context, the present study aimed to explore the lived experiences of siblings of individuals with ASD. A qualitative study design using the approach of IPA was used. The primary objective was to explore the lived experiences of siblings of ASD individuals while the secondary objectives of the study were (a) to explore the sibling's perspective on the process of discovery of ASD, and (b) to examine the impact of ASD on perceived needs and sources of support for the siblings.

## Materials and Methods

### Sample

Siblings of individuals with Childhood Autism, Asperger's Syndrome, Atypical Autism or Other Pervasive Developmental Disorders as per ICD-10,<sup>15</sup> who were above 15 years of age and lived with the child with ASD at least till completion of secondary education (which corresponds to 15–16 years duration), were recruited in the study. The age and education criteria imply that the participants are at least adolescents who will have adequate cognitive capacities for reflecting and narrating their life experiences. Siblings with any developmental condition or psychiatric illnesses were excluded by asking the parents if there has been any felt need for psychiatric consultation, developmental concerns, or hospitalization in the past. Fourteen siblings, including five for the pilot study, were recruited from two local schools for people with ASD and other neurodevelopmental disabilities in Bangalore, India, and from the out-patient Child and Adolescent Mental Health Units of the of the National Institute of Mental Health and Neurosciences (NIMHANS), Bangalore, through convenient sampling. Four siblings were from the out-patient departments and the rest were recruited from schools. The data collection was started in December 2017 and ended in February 2018. Recruitment was continued till the timeline planned for data collection ended because it was part of a M.Phil. research, where the timeline for data collection had to be specifically defined. However, based on the existing clinical data at our center, we anticipated to cover adequate sample within this timeline that is necessary for data saturation.

### Tools

A sociodemographic checklist was developed for this study to record the minimum relevant sociodemographic variables. These included age, education, occupation, and socioeconomic status of the people with ASD, siblings and their parents, which served as important background information to understand

the nature of the sample. Indian Scale for Assessment of Autism<sup>16</sup> was used to assess the severity of ASD in the person with ASD. To understand the lived experiences of siblings, a "Semistructured Interview Schedule to Explore the Lived Experiences" (SISEL, available as an online-only supplementary file) was constructed with open-ended questions, keeping in mind the context as well as cultural factors.

### Procedure

The study was conducted in two phases after obtaining clearance from the Institute's Ethics Committee of NIMHANS, Bangalore.

#### Phase 1: Development of SISEL

A conceptual framework that allows probing, with 18 open-ended questions, was developed by reviewing the literature<sup>15,17,18</sup> and brainstorming by the authors. The questions were on the broad themes of discovering the condition, processing the information about the condition, perceived impact and coping, concerns, and future care. However, the framework allowed themes to emerge naturally in the process of interviewing. The draft schedule was reviewed by six experts from the field of developmental disabilities ( $n = 3$ ) and clinical psychology ( $n = 3$ ), who have more than two decades of experience of working with children with ASD. They rated the questions on clarity, relevance, and appropriateness. The interview schedule was revised accordingly, thus establishing content validity. A pilot study was done with five siblings. Based on the responses, two more questions were added to the draft schedule. As the pilot data was included in the analysis, the siblings were contacted again to answer the two questions that were added later.

#### Phase 2: Data Collection and IPA

After seeking written informed consent and assent from the participants and their parents as required, the sociodemographic checklist, ISAA, and SISEL were administered in the privacy of their homes. The questions were asked in the pre-established sequence, with probes when required. Each interview lasted for 45–55 minutes, and they were audiorecorded with due permission. Behavioral observations and change in tone and

expression of emotions were noted down. Debriefing was done after every interview. The interviews were transcribed manually by the interviewer (PV) using InqScribe, Version 2.2.4, by Inquirium. The software has the option to listen to and pause the recording on one side and adjust the speed of the audio to simultaneously type the transcript on the other side. The audio and text files were stored in a password-protected folder on a laptop and hard disk with the researcher (PV). The recorded interviews were retained with the researcher for a period of six months after completion of the study as it was a nonfunded dissertation, and the data could not be retained for a longer period after completion of the course. The same was mentioned in the consent form.

## Data Analysis

Descriptive statistics was applied manually to analyze the demographics and clinical variables. The phenomenological analysis was done following the guidelines given by Pietkiewicz and Smith<sup>19</sup> and it included the following four steps: (a) *Multiple readings and making notes*: Each participant's audio recording was listened to and transcript was read multiple times to attain an essence of the meaning in the experience of the participant, and notes were made with regard to overall observations and inferences from each transcript followed by inferences about specific segments of the interviews. (b) *Transforming notes into emergent themes*: The initial notes about the content of the interviews were then transformed into emerging themes. A concise phrase that is at a more abstract level and involves a psychological conceptualization was recorded in the right-hand-side margin. (c) *Seeking relationships and clustering themes*: This stage involves identifying relationships between similar themes and clustering them together based on a concept and providing a descriptive label for each category. This was done by noting all the emergent themes of each participant's interview separately and grouping similar themes together and labelling the category of themes. (d) *Deriving superordinate and subordinate themes*: The categories from the interviews from all the participants were considered together, and similar categories were clustered. The concept that they fell under formed the

superordinate theme, while the different domains under this theme formed the subordinate themes.

The data was analyzed by one author (PV). In addition, two (10%) transcripts were randomly selected by another author (TK) and analyzed, to ensure consensus on superordinate and subordinate themes. The data analysis process was undertaken from February 2018 to April 2018. Each protocol took about eight hours for transcription and thematic analysis.

## Results

### Phase 1: Sample Characteristics

Fourteen siblings participated in the study, including 12 females and 2 males. They were aged 15–36 years, and the mean age was 22.85 (*SD* 5.97) years. All the participants were from middle or higher socioeconomic status, with well-educated parents. There were students, professionals, and a homemaker among the participants. Three were married (**Table 1**).

**TABLE 1.**  
**Summary of Sociodemographic Variables of the Siblings in the Main Phase (*n* = 14)**

| Variable        | Subcategories     | <i>M</i> ( <i>SD</i> )/ <i>n</i> (%) |
|-----------------|-------------------|--------------------------------------|
| Age (in years)  |                   | 22.85 (5.97)*                        |
| Sex             | Male              | 2 (14.28)                            |
|                 | Female            | 12 (85.71)                           |
| Marital status  | Married           | 3 (21.42)                            |
|                 | Unmarried         | 11 (78.57)                           |
| Education       | Current schooling | 3 (21.42)                            |
|                 | Current UG        | 2 (14.28)                            |
|                 | Undergraduates    | 6 (42.85)                            |
|                 | Postgraduates     | 3 (21.42)                            |
| Occupation      | Student           | 5 (35.71)                            |
|                 | Professionals     | 8 (57.14)                            |
|                 | Homemaker         | 1 (7.14)                             |
| No. of siblings | One               | 11 (78.57)                           |
|                 | Two               | 3 (21.42)                            |
| Birth order     | One               | 11 (78.57)                           |
|                 | Two               | 3 (21.42)                            |

\**M* (*SD*).

**TABLE 2.**  
**Sociodemographic Details of Individuals with ASD (*n* = 14)**

| Variable         | Subcategories | <i>M</i> ( <i>SD</i> )/ <i>n</i> (%) |
|------------------|---------------|--------------------------------------|
| Age (in years)   |               | 19.92 (5.14)*                        |
| Sex              | Male          | 12 (85.71)                           |
|                  | Female        | 2 (14.28)                            |
| Age of diagnosis | ≤5 years      | 9 (64.2)                             |
|                  | 6–10 years    | 1 (7.14)                             |
|                  | >20           | 2 (14.28)                            |
| Severity of ASD  | Unsure        | 2 (14.28)                            |
|                  | Mild          | 11 (78.57)                           |
|                  | Moderate      | 2 (14.28)                            |
|                  | Severe        | 1 (7.14)                             |

\**M* (*SD*). ASD: autism spectrum disorder.

The individuals with ASD were 12–32 years old, with 12 females and 2 males. The majority were diagnosed by the age of five years. On ISAA, 11 individuals were found to have mild ASD, 2 had moderate ASD, and 1 had severe ASD (**Table 2**).

### Phase 2: Interpretative Phenomenological Analysis

Six superordinate themes emerged from the analysis of the interviews. These were (a) processing and understanding the condition, (b) coping with challenging experiences, (c) current and future roles, (d) needs and expectations, (e) support system, and (f) positive aspects of the sibling relationship. Each superordinate theme, with the corresponding subordinate themes and subthemes, is represented below. The results are presented in **Table 3**. The excerpts from interviews representing each theme are presented in supplemental table (**Table S1**).

#### Superordinate Theme 1: Processing and Understanding the Condition

It was related to how the siblings discovered ASD, understood it, acquired information, and went through the process of accepting the differences.

*Subordinate Theme 1.1: Recognizing the Differences.* Though the presentation of ASD is varied, siblings initially noticed the behavioral differences in the siblings with ASD. Some recognized it very early, and others recognized it later from social interaction, communication, and behavioral difficulties. Behavioral

**TABLE 3.**  
**The Interpretative Phenomenological Analysis Showing Various Themes of the Lived Experiences of the Siblings**

| Superordinate Themes                       | Subordinate Themes                                | Subthemes  |
|--|---|--|
| Processing and understanding the condition | Recognition of differences                        | <ul style="list-style-type: none"> <li>Deficits in communication and social interaction (n = 12)</li> <li>Behavioral dysregulation (n = 4)</li> <li>Implicit understanding (n = 2)</li> </ul>  |
|  | Knowledge and awareness                           | <ul style="list-style-type: none"> <li>Lack of awareness (n = 10)</li> <li>Clarity after diagnosis (n = 5)</li> <li>Sources of information (parents (n = 6), professionals (n = 5), books &amp; internet (n = 4))</li> </ul>   |
|  | Developing acceptance                             | <ul style="list-style-type: none"> <li>Process of grief (n = 3)</li> <li>Acceptance (n = 9)</li> </ul>   |
| Coping with challenging experiences        | Nature of challenges                              | <ul style="list-style-type: none"> <li>Emotional (n = 14)</li> <li>Relational (n = 10)</li> <li>Social (n = 12)</li> </ul>   |
|  | Coping with challenges                            | <ul style="list-style-type: none"> <li>Suppression and avoidance (n = 10)</li> <li>Rationalization (n = 6)</li> <li>Normalization (n = 4)</li> <li>Maximizing positives (n = 3)</li> </ul>   |
| Current and future roles                   | Supportive and parental role (n = 12)             | Nil  |
|  | Anxiety related to future care and plans (n = 12) | Nil  |
| Needs and expectations                     | Needs for sibling with ASD                        | <ul style="list-style-type: none"> <li>Independence (n = 6)</li> <li>Achievement (n = 3)</li> <li>Improvement in symptoms (n = 3)</li> <li>Resources (n = 9)</li> </ul>  |
|  | Self-needs  | <ul style="list-style-type: none"> <li>Understanding (n = 5)</li> <li>Social life (n = 5)</li> <li>Autonomy (n = 2)</li> <li>Emotional support (n = 4)</li> <li>Career (n = 2)</li> <li>Information (n = 4)</li> <li>Attention from parents (n = 3)</li> <li>Typical sibling relationship (n = 5)</li> </ul> |
|  | Perceptions about and reactions to needs          | Nil  |
| Support system                             | Individuals in the support system                 | <ul style="list-style-type: none"> <li>Parents (n = 12)</li> <li>Professionals (n = 5)</li> <li>Siblings (n = 2)</li> </ul>  |
|  | Perceptions about the support system              | <ul style="list-style-type: none"> <li>Strong support vs. lack of support (n = 6)</li> <li>Barriers to support seeking (n = 8)</li> </ul>  |
| Positive aspects of sibling relationship   | Nature of support                                 | <ul style="list-style-type: none"> <li>Practical (n = 10)</li> <li>Financial (n = 4)</li> <li>Emotional (n = 3)</li> </ul>   |
|  | Self-development                                  | <ul style="list-style-type: none"> <li>Increased sensitivity and empathy (n = 5)</li> <li>Learning life lessons (n = 3)</li> <li>Higher sense of responsibility (n = 3)</li> </ul>   |

condition and delay in diagnosis that has been reported. Many siblings experienced a sense of relief after a name was given to the condition during the process of diagnosis, as it made things much clearer compared to the vague understanding they previously had about their sibling. The interviews revealed that siblings acquired information about the condition from different sources such as parents, professionals, books, and with technological advancement, the internet as well.

*Subordinate Theme 1.3: Developing Acceptance.* Siblings overcame their initial difficult emotions and moved toward accepting the condition as they understood it better. The process of grief, which involved moving from shock to the search for a solution, sadness, and finally toward acceptance, can be understood from excerpts from interviews.

**Superordinate Theme 2: Coping with Challenging Experiences**

All the siblings reported of facing many challenges as they grew up with a sibling with ASD, but a few had positive experiences also.

*Subordinate Theme 2.1: Challenges.* The nature of challenges varied, but each situation was associated with difficult emotions. While most of the challenges seem to be related to the sibling relationship and the family setting, one that stands out is the aggressive behaviors of the sibling with ASD, and another is social stigma. This experience gives an account of how the behavioral dysregulation in the individual with ASD poses a threat and leads to distress and embarrassment to the neurotypical sibling.

Many siblings also experienced differential treatment by their parents, but they did not report it spontaneously. When probed about it, many brushed it away or minimized it.

Behavioral problems in the individual with ASD led to embarrassment and social isolation. Though most of the siblings developed acceptance over some time, they also wished that their sibling was like a typically developing individual. Some siblings expressed that they missed performing the roles they would have to play if they had a typically developing sibling.

dysregulation such as aggression, demanding behaviors, and hyperactivity were some of the differences initially noted by some siblings. While most siblings were able to report specific difficulties and differences that they noticed in the individual with ASD, some describe it as more of an implicit process of understanding, where they describe it

to be something that they just knew but cannot point to any specific differences.

*Subordinate Theme 1.2: Knowledge and Awareness.* Though siblings were able to recognize the “differences” in the individual with ASD at a young age, awareness about ASD came much later. There is lack of adequate knowledge about the



Siblings expressed a wide range of emotions including anger, anxiety, frustration, feeling neglected, regret, sadness, and loneliness. Many siblings described their anxiety related to thoughts about the future, while one sibling narrated about the time when she had to undergo stigma related to her health condition secondary to having a brother with ASD. Both the male siblings in the study reported feelings of loneliness.

*Subordinate Theme 2.2: Coping with Challenges.* Though the siblings reported of using diverse coping strategies, some strategies such as suppression, avoidance, or minimizing of emotions were reported by all. Siblings also normalized the sibling's difficulties and the nature of the sibling relationship. The siblings expressed that, over time, acceptance of the individual with ASD is a process that helps them to deal with their challenges. Another strategy that a few siblings seemed to use was maximizing the positives in the sibling and the sibling relationship.

### Superordinate Theme 3: Current and Future Roles

The siblings performed diverse roles such as assisting in self-care, school work, and training and participating in consultations. Also, protecting the individual from stigma and harm and readiness to accept caregiver roles in the future were observed in many participants.

*Subordinate Theme 3.1: Roles and Responsibilities.* Many siblings had assisted their parents or taken complete care of the person with ASD. Some siblings were expected to play a protective role when they go out with their siblings with ASD or when the latter is bullied or discriminated. Some offered different kinds of support such as financial, emotional, and practical support for their sibling with ASD.

*Subordinate Theme 3.2: Future Care and Support.* One of the salient themes in many interviews was the concern and anxiety related to future care and support that most siblings expressed. A few siblings expressed ambivalence about prioritizing their own needs or their sibling's needs. Siblings expressed concerns mainly related to the sacrifice of their career goals and autonomy. Several

siblings expressed their concerns about the independent living of the sibling with ASD in the future.

### Superordinate Theme 4: Needs and Expectations

Siblings often reported their needs for the sibling with ASD, rather than their own needs, unless probed.

*Subordinate Theme 4.1: Needs for the Sibling.* Apart from future independent living, the siblings also wished improvement in the symptoms and academic achievement. One sibling described her needs for improvement in the sibling's symptoms to fulfil the vision and dreams that she has for her sibling. The need for resources was expressed by a few siblings as well.

*Subordinate Theme 4.2: Personal Needs.* Some siblings expected better understanding from significant others about their own needs and challenges. Some also expressed a need to have a better social life. Some siblings felt that their own need for emotional support has been neglected due to increased investment in time and care for the sibling with ASD. There was also a need for more information about dealing with their sibling's challenges. In retrospect, siblings also recognized a felt but unmet need for parental attention. Finally, another important need recognized was the need for autonomy and understanding.

*Subordinate Theme 4.3: Perceptions or Reactions to the Needs.* As mentioned earlier, siblings usually hesitated to express their needs, and even when they did, they tended to minimize them or felt ambivalent about them.

### Superordinate Theme 5: Support System

As the siblings live and grow with a person with ASD, they tend to draw support from parents, professionals (teachers, doctors), friends, and other siblings.

*Subordinate Theme 5.1: Individuals in the Support System.* Almost all siblings except for two reported that they looked to their parents for support. Siblings turned to professionals when they need information about training or dealing with the sibling's behavioral or academic difficulties.

*Subordinate Theme 5.2: Perceptions About the Support System.* Most siblings had mixed perceptions about the social support system. One sibling perceived a lack of support from extended relatives. Siblings also perceived some barriers to seeking social support, such as lack of awareness or perceiving themselves to be a burden.

*Subordinate Theme 5.3: Nature of Support Needed.* Siblings mainly sought emotional or practical support in dealing with challenges related to the individual with ASD. Besides, they also wished to talk to siblings of other individuals with ASD.

### Superordinate Theme 6: Positive Aspects of Sibling Relationship

In this study, positive aspects refer to any emotions, incidents, perceptions, activities, or development that contributed to the well-being or were perceived as beneficial by the sibling.

*Subordinate Theme 6.1: Strong Bond.* Many siblings described experiences that contributed to the development of a strong, loving, and affectionate bond between the siblings. Despite challenges in the relationship, many siblings chose to express their feelings of affection toward the sibling with ASD. One sibling expressed her pride related to her sibling's independence in certain aspects. Some siblings reported that they do not share a relationship as siblings in other families do, and a few reported how it is indeed better than that of others.

*Subordinate Theme 6.2: Self-development.* Participants identified that a sibling with ASD contributed to a meaningful experience by enriching values such as sensitivity, compassion, empathy, and a higher sense of responsibility.

## Discussion

The purpose of the study was to understand the lived experiences of siblings of individuals with ASD. We identified six themes: processing and understanding the condition, coping with challenging experiences, positive aspects of the sibling relationship, current and future roles, support system, and needs and expectations. Some of these themes have been identified in earlier studies, too.<sup>20</sup>

## Awareness of Differences Is Not the Same as Understanding ASD

The majority of the siblings were aware that their sibling with ASD was different. However, they did not know specifically that it was due to ASD. They mainly noticed speech and communication difficulties, which are the hallmark of ASD. This was the case despite the presence of more prominent behavioral oddities and emotional dysregulation as reported in previous studies.<sup>21</sup> As per previous studies, siblings prefer to know from credible sources, such as parents and professionals, about what ASD is,<sup>9</sup> but many would discover it through a long drawn process, with periods of uncertainty and a general lack of awareness.<sup>22</sup> The process of developing understanding and awareness about the condition seemed to be poorly supported and long-drawn for the siblings in this study. This possibly reflects poorer resources available in India to promote understanding of the condition,<sup>14,23,24</sup> making the lived experience more challenging. The lack of systematic avenues to understand ASD is not unique to siblings and also affects families and parents as found in literature.<sup>14,23,24</sup> Since siblings have specific roles and responsibilities, it is important to facilitate an age-appropriate level of discussion about the nature of ASD and the needs it raises.

## Lived Experiences Are Predominantly Negative

While all siblings had negative experiences in this study, some reported positive experiences. The negative experiences were similar to what has been described in the previous studies,<sup>7,11</sup> but having to deal with aggressive behaviors, lack of family recreational time, lack of social life, and reduced attention from parents have been more explicitly mentioned in this study. As noted in previous studies,<sup>25-27</sup> many siblings reported experiencing social stigma, especially in the context of play and school. Many studies have reported that stigma toward ASD is a pressing issue even in high-income countries.<sup>27</sup> However, in an Indian setting like this study's, lack of awareness and not opening up discussion about ASD seem to contribute

to stigma in the society.<sup>26</sup> Siblings might be significantly impacted by stigma as they are closer in age to the person with ASD and tend to spend more time in activities like play or may also go to the same school where they may experience stigma not only the child with ASD but also the sibling. These kind of situations might push the siblings to "grow up" to support the sibling with ASD at an early age itself. As also noted in the previous studies,<sup>7,28</sup> perceived stigma was high among siblings who were sensitive to embarrassment or have expectation for greater acceptance of people with ASD in the community. Thus, these findings support the results of previous studies that siblings will have both positive and negative lived experiences, with more older siblings reporting of more positive experiences.<sup>11</sup> In the current study, despite the negative experiences, siblings spoke more about the needs of the sibling with ASD over their own needs. Many older siblings reported that appreciating the uniqueness of the person with ASD led to empathy and a strong sense of love and care for others in previous literature.<sup>7,9,11,29</sup> As some of these siblings described, it was probably a process of "developing strength through challenges."

## Emotional Experiences Are Similar to Grief Reactions

Literature shows that siblings experienced feelings of loneliness and anxiety as part of their lived experiences. A few studies reported that some sibling experience shock and anger as they become aware of the differences in their sibling, however the majority of them may eventually move toward acceptance.<sup>30</sup> The current study found that as coping mechanisms, the siblings, especially the older ones, will minimize their own emotions, normalize the experiences, and focus on the positive experiences. This appears to be somewhat similar to the processes of grief resolution in which the siblings move from the perception of specific losses (e.g., routines, socioemotional needs, and the fear of uncertainty) to accepting the life situation and coping with it, which have been found in previous studies.<sup>2,7,29</sup> Awareness of the condition and a supportive attitude of the family can help the siblings

overcome stigma and negative emotions. The role of friends as support seems to be relevant when siblings are older and are looking for coping resources beyond the family and parents, which is found in both the current study as well as the literature.<sup>31</sup>

## Roles Are Permeable, but the Supportive and Protective Role Is Constant

Siblings were expected to perform diverse roles; however, supportive and protective roles were common. The siblings in the current study implicitly described sibling-focused parentification, with mixed feelings of pride in supporting the family and some regret over not having an adequate social life. As previous studies have also noted,<sup>9,32</sup> worries about future caregiving role in the absence of the parents were common. However, worries about the future are not unique to ASD but also reported in intellectual disability.<sup>18</sup> Since worries about future caregiving-roles will affect the quality of sibling relationships,<sup>33</sup> it is important to assist siblings in making informed decisions about the same.

## Personal Needs Take a Backseat over the Sibling's Needs

Siblings will have unique needs as they grow up with a sibling with ASD. However, they may not report their personal needs spontaneously as much as they report the needs of the sibling with ASD. If at all they report any needs, according to previous studies, it is mostly related to unmet emotional and social needs.<sup>9,11,21,22</sup> A similar phenomenon has also been noted in other studies where caregivers, especially mothers, talked more about the needs of the child with intellectual disability than their personal needs.<sup>34</sup> One of the main sources to meet social and emotional needs is the parents and family members, and at a later stage, friends and professionals. As much as the lack of awareness about formal support systems, cultural expectations to pursue collective goals than one's personal goals may also be contributing to it. As noted in other studies, neurotypical siblings may not express the need for parental companionship or

emotional support overtly, as parents are already preoccupied with the condition of another child.<sup>35</sup> The minimizing of their own personal and career needs and increasing their investment in the family might also be a compensatory strategy that siblings use to be “the good child” in the family. Thus, both the current and a previous study show that in the absence of appropriate formal support, siblings will appear ambivalent of meeting personal needs.<sup>21</sup> In this context, there is a need to strengthen formal support services in the community to provide positive behavioral support to siblings to effectively meet their personal needs. Since the siblings will have many goals, it is important to delineate proximal and distal targets to maintain a clear intervention focus and then shape the content and delivery framework accordingly.<sup>33</sup> Such programs can also involve parents because siblings value parental support.<sup>10,11,30</sup>

However, the study has limitations. Sample size was small, with a wide age range of the participants. The findings could be generalized more to female siblings and those from middle or higher socioeconomic status and urban background, because of the sample characteristics. All the participants had access to mental health resources. More research would be required to understand the experiences of male siblings and those from lower socioeconomic and rural backgrounds. The qualitative analysis was done mainly by one researcher, with checking of the coding by another researcher. Though analysis by multiple raters may not have ensured reliability due to the subjective nature of IPA, it might have added to the validity.

In conclusion, the lived experiences of siblings seem to be different from the parents. While the lived experiences were predominantly negative for many siblings, some of them also reported transformational experience coinciding with greater understanding of ASD. The findings highlight the need for involving siblings in the family support programs as early as possible and extending appropriate support to them. Further research needs to focus on objective methods of analysis with larger samples, include siblings from all backgrounds and lower age ranges as well as male siblings.

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## Appendix I

### Semistructured Interview Schedule to Explore the Lived Experiences (SISEL).

1. When did you first feel that there was something different about your sibling?
2. When you realized that your sibling was different from others, how did you deal with it?
3. Has anyone told you about the condition your sibling has?
4. What do you remember being told about Autism by anyone the first time?
5. Would you kindly describe how you reacted when you were told about Autism in your sibling?
6. What were your thoughts when you knew that your sibling was diagnosed with Autism?
7. What did it mean to you that your sibling had Autism?
  - a. Probe: I understand that this is not something that you might have felt overnight. How did this change come about?
8. What do you think is the impact of Autism on your sibling?
9. What is it like to live with a sibling with Autism?
10. If the response to the above question is regarding positive experiences:

Could you tell about any challenges of growing up with your sibling?

If the response is regarding negative experiences:

Could you tell about any positive experiences of growing up with your sibling?

Probe: How did you deal with the difficult experiences that you have had?

11. What is your current role in your sibling's life?

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