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Growing up with a Sibling who has a Developmental Disability: Quality of Life in the Eyes of Parents

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Abstract

Living with a sibling who has a developmental disability (DD) like autism spectrum disorder (ASD), or intellectual disability (ID) can impact the siblings in diverse ways. This study examines the quality of life for children growing up with a sibling with DD from the perspective of parents. We interviewed eight parents (6 mothers and 2 fathers). We explored three superordinated themes using interpretive phenomenological analysis: the life domain of siblings,' lifespan siblings, and parental involvement. The findings showed that parents reported both positive and negative experiences, indicating that having a sibling with a DD influenced siblings' quality of life. Among these, social support and trust in well-being are strongly linked with positive outcomes: acceptance, forbearance, mutual understanding, experience sharing, and dealing with the outside world, reflected in mixed responses. Age has a greater influence on the lifetime sibling theme; however, achieving a balance in parental involvement is essential for successful results. In conclusion, having a sibling with DD can impact the lives of siblings without DD in both positive and negative ways. The negative effects encompass difficulties in having joint activities and mutual understanding, whereas the beneficial elements entail heightened trust in well-being and social support. The dynamics of relationships and parental engagement significantly contribute to improving siblings' quality of life. Enhancing connection dynamics and understanding the extent and nature of parental participation elevate the quality of life for both typical and atypical children during their developmental years.

*Keywords***:** children with developmental disability, parents, quality of life, siblings

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Introduction

The experience of growing up with siblings who have developmental disabilities can significantly shape family dynamics and individual life outcomes. Developmental disabilities encompass a wide range of conditions, which include autism spectrum disorder (ASD), attention-deficit/hyperactivity disorder (ADHD), intellectual disability (ID), communication disorders, specific learning disorders (SLDs), and neurodevelopmental motor disorders like tic disorders and Tourette syndrome (TS) (Antolini et al., 2023). These conditions encompass a range of challenges that affect an individual's physical, cognitive, and emotional development. The disorders typically manifest early in development, often before the child enters grade school, and are characterized by developmental deficits that produce impairments of personal, social, academic, or occupational functioning (American Psychological Association, 2013). Thus, implying DD influence not only on the child with DD, but also on the broader family that the child is living in.

Siblings of individuals with developmental disabilities often play a significant role in the family dynamic. They may take on caregiving responsibilities, provide emotional support, or navigate complex relationships with their disabled siblings, shaping their perspectives and experiences in the process. Social, emotional, and financial factors can greatly impact the quality of life, which can also affect their own physical, mental, and emotional well-being (Siminghalam et al., 2018). Consequently, research shows that society needs to reconsider its views on disability to enhance the quality of life for siblings of children with developmental disabilities (Kotzampopoulou, 2016).

Empirical studies show inconclusive outcomes for siblings growing up with children who have developmental disabilities. Sommantico et al.(2020) have shown that sibling relationships can have both positive and negative effects on the psychological outcomes of both siblings with and without disabilities. Literature on sibling relationships, when one child has a developmental disability, demonstrates varying findings. Researchers argue that the siblings of children with autism are likely to experience psychological maladjustment, poor self-concept, and impaired social competence (McHale & Gamble, 2007). Luijkx et al. (2016) studied the experiences of siblings of children with multiple disabilities, including severe intellectual disability, and found that having a sibling with a disability impacted siblings' overall quality of life. On the other hand, research has found that having a sibling with autism engenders positive outcomes, with this cohort of children displaying higher levels of social competence and more positive behavior adjustment than children who do not have a sibling with a disability (Bachraz & Grace, 2009). Taken together, these findings suggested that sibling outcomes are mixed, being influenced by context, relationship, and individual factors.

Siblings play a crucial role in shaping each other's character, providing support, companionship, and shared experiences. Siblings often have a strong bond that lasts a lifetime (Tozer et al., 2013). In their relationship, siblings learn to love, take care of each other, and establish their ways to communicate, play, and interact (Cuskelly & Gunn, 2003; Diener et al., 2015). In families where one child has a disability, often siblings are involved in helping, teaching, and caretaking roles, and these behaviors enhance a sense of connectedness and foster sense of responsibility and empathy (Bachraz & Grace, 2009).

Strong sibling relationships create a supportive environment for children to express their emotions and cultivate essential life skills. Siblings' relationships play a significant role in identity construction and provide opportunities for skill development and positive emotions like pride and joy (Vella Gera et al., 2021). Through mutual learning and support, siblings help boost each other's self-esteem and foster a sense of achievement. These relationships are instrumental in shaping children's emotional development and overall well-being. Thus, the nature of the siblings' relationship is crucial as the outcome depends on it.

Siblings of children with DD might face emotional difficulties despite all the possible advantages. Lemoine and Schneider (2022) noted negative feelings that can arise when one sibling has developmental disabilities (DD), such as guilt, jealousy, or feeling deprived of parental attention. Especially when the sibling with the developmental disorder is the oldest, younger siblings may struggle to follow their lead and accept the disability as a challenge (Lemoine & Schneider, 2022). Similarly, Luijkx et al. (2016) reported that siblings sometimes struggle to accept their brother or sister's disability. They also shared positive experiences of enjoying activities together and feeling happy when their sibling is content.

These challenges may be intensified in low-resource countries and stigmatizing contexts. In countries like Ethiopia, children with developmental disorders are seen as a curse or result of sin, magnifying the stigma and discrimination in the community. Families in these situations may face a lower quality of life and changes in family dynamics. Siblings of individuals with developmental disorders may find it difficult to accept and support their siblings. Finding appropriate support can be a challenge, as families may not know how to best help their children with developmental disorders. Research conducted by Dunifon et al. (2017) indicates that siblings tend to interact more with each other than with their parents. When a developmental disorder is present in the family, it can impact the relationship and interactions between siblings. It is crucial to acknowledge the emotional, social, and psychological needs of siblings who are not affected by the disorder. Understanding how siblings view their roles within the family dynamic is essential to promoting the overall well-being of the family.

Family systems theory describes families as interactive, interdependent, and reactive: if something affects one family member, it affects all family members (Seligman & Darling, 2009; Turnbull & Turnbull, 2001). By examining the quality of life of children who have siblings with developmental disorders, we can provide better support and enhance the well-being of all family members. According to Moyson and Roeyers (2012), quality of life (QoL) is a personal and subjective experience, defined in their study as having a life that is good and meaningful. Quality of life research acknowledges the impact that having a child with a disability has on family dynamics, including the perspective of siblings (Kyrkou, 2018).

Despite increased recognition of these families' unique experiences, there is still a lack of empirical data on parental perspectives of the quality of life of siblings growing up with children with DD. Understanding the subjective experiences of siblings from their parents' perspectives can highlight the family's stance on the siblings and children with DD, plus the parents' involvement in the children's relationship, informing interventions and support programs and leading to better outcomes for families, as well as contributing to the development of resources specifically tailored to assist the siblings. Furthermore, they could be useful for professionals and researchers dealing with families of people with developmental disabilities.

Research Questions

The study sought to answer the following research questions.

- How does having a sibling with a developmental disability affect the sibling's quality of life from the parents' perspective?
- How do sex and age influence sibling relationships, if at all, in families where one sibling has a developmental disability?
- How well do parents comprehend their children who do not have a developmental disability in comparison to their children with developmental disability?

Growing up with siblings who have DD presents unique challenges and opportunities that shape family dynamics. This study explores the daily experiences of children who have siblings with DD. By examining quality of life from the perspective of parents, this discussion aims to highlight the resilience, struggles, and support systems that play crucial roles in improving the quality of life for these siblings. The findings from this study can help concerned bodies (e.g., centers that serve children with DD) to be aware of the importance of siblings in the lives of children with DD. The findings can also contribute to a better understanding of the challenges and resilience of families who have a child with DD.

Methods

Study Design

For this study, the researchers utilized a qualitative research approach. The study employed a phenomenological research design as it aids in exploring parents' lived experiences with a focus on understanding the meaning behind those experiences.

The Setting of the Study

The research was conducted at two (one private and one public) schools/centers that provide services to children with disabilities. The centers are located in Addis Ababa. The public school is actively engaged in providing educational support to children with special needs. On the other hand, the private center, apart from educational programs, offers awareness training to parents, physical therapy for children, and other forms of support. Both have been committed to these causes for years. The public school opens its doors to all children with disabilities, while the private center specifically focuses on autism spectrum disorder.

Participants

As shown in Table 1, the qualitative data were gathered from eight participants: six of them were female (i.e., mothers), while two of them were male (i.e., fathers). The researchers employed a purposive sampling technique to select eight parents who have more than one child, ensuring that at least two of the children met the criteria: one with DD and another typical child aged over six years.

Children around the age of four or five may start to notice and ask questions about differences they observe in their siblings' behavior or abilities (Slaughter & Brown, 2011). However, their understanding of what it means to have a developmental disorder is limited at this stage. Typically, around ages 6 to 8, children may have a better grasp of the concept and recognize that their siblings' challenges result from the disorder (Gawish, 2023).

Table 1

Participants' Profile

S. No.	Participant code	Participant relation with the child with DD	Marital Status	Number of children	Age in years of Siblings	Which child is with DD
1	M008	Mother	Married	4	22, 18, 12, 7	3rd born boy
2	M009	Mother	Widowed	2	18, 7	2nd born girl
3	F014	Father	Married (2nd marriage)	4	44, 26, 10, 8	4th born girl
4	M016	Mother	Married	4	15, 11, 6, 6	2nd born boy
5	M017	Mother	Divorced	3	24, 18, 13	3rd born boy
6	F020	Father	Married	3	10, 8, 3	2nd born boy
7	M021	Mother	Married	2	18, 14	2nd born boy
8	M022	Mother	Married	4	27, 26, 23, 15	3rd born boy

Instruments

This study employed semi-structured interviews to collect data from the participants. Primarily, the researchers used the Siblings' Quality of Life Scale developed by Moyson and Roeyers (2012), which comprises nine domains, as a framework to develop the semi-structured questions for the interview. Each domain informed one or more interview questions, allowing the parents to describe their experience while ensuring conceptual coverage.

Consistent with the nature of semi-structured interviews, questions were phrased in a way that allowed flexibility, and additional follow-up questions were used to ask for more information and encourage elaboration. Besides, every effort was made to make the participants understand the questions first. These included changing the wording of the questions and using familiar terms for the participants. Furthermore, the interview guide and the actual interviews were conducted in Amharic to ensure participants' understanding.

Data Collection Procedures

The first author conducted the interviews face-to-face in April 2024 using a semi-structured interview guide. After explaining the purpose of the interview, the researcher asked each participant's willingness to participate. After ensuring that all participants were willing to participate, the researcher also asked about their willingness to audio-record the interview sessions. Based on the interviewees' consent, the interview sessions were audio-recorded, taking an average of 37 minutes each. At the same time, the researcher took brief notes to write a summary of the main points raised in each interview.

Data Analysis Techniques

In this study, interpretive phenomenology is utilized as the data analysis method. Interpretive phenomenology is a commonly used method for analyzing data in studies that aim to inquire into and understand the lived experiences of the participants (Willig, 2002).

Audio-recorded data were transcribed manually. Each transcript was read repeatedly to ensure immersion in the data. Detailed line-by-line interpretive coding was conducted, from which emergent themes were developed within each individual case. Following within-case analysis, patterns of convergence and divergence were examined across cases. These iterative processes revealed three superordinate themes that were identified: (1) life domain of siblings, (2) lifetime sibling relationships, and (3) parental involvement. The life domain of siblings was interpreted in relation to Moyson and Roeyers's (2012) Quality of Life nine-domain framework; however, the framework informed the organization and interpretation of findings rather than directing the coding process. Across these three superordinate themes, 18 interconnected subthemes were identified, which depict the profound experiences of siblings as perceived by their parents.

Findings

Eight parents, consisting of two fathers and six mothers, provided data for this research. Each participant is given an ID code for identification. The study focused on three interrelated superordinate themes that illustrate how children living with siblings who have DD are understood through their parents' perspective. The first parents' experiences are described in the life domain of siblings exploring, following the nine quality of life domains (Moyson & Roeyers, 2012). Second, the theme of lifespan siblings captures how sibling roles and relations evolve across developmental stages. Third, the theme of parental involvement highlights parental practices that shape sibling experience.

The superordinate theme of the life domain of siblings encompassed subthemes such as joint activities, mutual understanding, private time, acceptance, forbearance, exchanging experiences, trust in well-being, social support, and dealing with the outside world. The superordinate theme of lifespan siblings includes subthemes such as the best friend, caretaker-parental figure, and hostile neighbor. The superordinate theme of parental involvement included subthemes: understanding emotions, knowledgeability, carrying the yoke alone, and parental fairness.

By examining these superordinate themes and subthemes, we gain a comprehensive understanding of the experience of growing up with siblings who have a developmental disability from the parents' perspective, highlighting the quality of life that families in this unique situation face.

Participant Context

Participant M008 is a married woman with four children. Her third-born son has an intellectual disability (ID). She is a resolute stay-at-home spouse who primarily cares for her child, bearing the majority of the responsibility. The family faces economic challenges. Participant M009 is a widowed woman with two children. Her second-born daughter has ID. She serves as the primary breadwinner for the family, which is facing significant economic hardship. Occasionally, her son aids her in generating income. Participant F014 is a married man with four children from two marriages. His fourth-born daughter has a language disorder. His wife is a homemaker, and the family is financially stable. Participant M016 is a married woman with four children. Her second-born son has an ID. She is a devoted stay-at-home spouse who cares for her son. The family faces economic challenges, with the bulk of the responsibility falling on her shoulders. Participant M017 is a divorced woman with three children. Her third-born son has autism spectrum disorder (ASD). She is the primary provider for the family, as her adult children are dependent on her due to addiction issues. The family faces significant economic challenges, with her son's care being her top priority. Participant F020 is a married man with three children. His second-born son has ASD. His wife is a homemaker who cares for their son, although he is actively involved in the caregiving process. The family is financially secure. Participant M021 is a married woman with two children. Her second-born son has ASD. She is a resolute homemaker who primarily cares for her child. She decided not to have another child because of the burden she faced and in fear of having a child with a similar case. The family faces significant economic challenges. Participant M022 is a married woman with four children. Her second-born son has ASD. She is a homemaker who cares for her son with support from her husband and other family members, yet she is the primary caretaker of the child. The family is financially stable.

In general, we have six mothers and two fathers. The total number of siblings is twenty-six. Compared with the child with DD in the family, eight boys and four girls are older than the eight children with DD (six boys and two girls), while four girls and two boys are the younger ones. Two of the four older girls do not live with their sibling who has DD.

Life Domain of Siblings

This theme provided an organizing structure to explore parents' perceptions of siblings' experiences across relational, emotional, and daily-life dimensions. The analysis was structured around the nine-domain quality-of-life framework for siblings of children with developmental disabilities proposed by Moyson and Roeyers, while the interpretation was mainly grounded in participants' accounts. The nine subthemes include joint activities, mutual understanding, private time, acceptance, forbearance, exchanging experiences, trust in well-being, social support, and dealing with the outside world.

Joint Activities

As the age ascends, interest in joining in the activity descends, the parents explained. Age gap, interest in joint activity, and the kind and level of DD the child has also matter. So, when the sibling is younger (below the teenage years), the siblings have more activity. One father shared his experience, saying:

> My eldest son is disappointed because he always wished to have a brother or sister to play with and be close to. However, now that the younger son has autism, he does not know how to play and lacks interest in playing. The eldest son is eager to play, but the younger son is not. On the other hand, my youngest daughter is four years old. She enjoys playing with him and competing with him as well. (F020)

Parents have said that as their children without DD grow older, their level of participation and the types of activities they take part in together have decreased. The nature of a connection changes with time.

> As a mother, it was concerning to see my son’s situation, but he is doing better now. He is 23 years old, and his youngest sister is fifteen. They used to play and spend time together, but now he has shifted his focus to his younger cousin. His siblings take him to various places when necessary, but despite their efforts, I know he does not fit there. *(*M022)

Other parents who do not have younger children than those with DD reported that when their children interact with younger relatives or neighbors, they are treated and engaged better than older children. One of the participants supported this saying, "In the neighborhood, there are children, and they play and fight together" (F014). Across the range, parents have mentioned that the younger the siblings are, the better the chance of having common joint activities, and yet sex does not make any difference in this regard.

Mutual Understanding

All the parents agreed that there is often a lack of mutual understanding between siblings, with one side typically having a better grasp of matters than the other. This lack of understanding is attributed to the age gap between siblings and to their developmental levels, which affect their maturity.

> My son, who had the problem, likes to care for his younger siblings, and they love to play with him. They easily understand what he wants to say. They feel angry if anyone in the house makes him sad or angers him. They mostly side with him. *(M016)*

In general, respondents with siblings who are 10 years or older tend to have less emotional connection and understanding, leading to confusion. It is worth noting that when a sibling with DD is older and has a significant age gap with his/her younger siblings, there is a greater likelihood of mutual understanding and emotional bond. Another mutual understanding is evident in the way children without DD become more responsible towards their siblings with DD. Out of the eight participants, three mentioned that siblings develop emotional attachments, such as providing protection and being there for the child with DD.

> My son acts as a caring father figure to her, always putting her needs before his own. He values her happiness more than anything else, taking the time to utterly understand her emotions. Seeing her smile brings him immense joy. *(M009)*
>
> As I compare my first and third child to my second one over the years, I notice that their interactions are visibly evolving. My son, who has developmental disabilities, mostly existed in his own realm; how can he and the other kids attain mutual understanding? Conversely, I believe that the presence of siblings provides comfort to each child; could these interactions be considered a form of mutual understanding? (F020)

Private Time

Three participants reported that children are asked to stay home to care for their siblings with DD when the situation is dire, which leads to frustration and disruption of their schedules. Two parents mentioned that their children are too young to effectively care for another person, while three participants said that siblings do not mind taking on this responsibility. A mother said,

> My sons do not particularly enjoy spending time with their brother, who has a disability. While I understand their preference, I have seen that they tend to spend more time alone in their rooms, simply relaxing." (M008)

When it comes to birth order among siblings, parents have explained that it holds no significant importance. As children grow older, they become more interested in having their own space and time. Conversely, younger children are more inclined to spend time with their siblings. Parents have noted that siblings with DD often have opportunities for private time because the responsibility of caring for their siblings falls primarily on the parents, particularly mothers. Although half of the parents are not satisfied with how their siblings use their time, the parents consider that the children are satisfied with having time for themselves.

> We did not ask my son to care for his sister because my wife was home. They are both kids, of course. Maybe the only responsibility we give him is to look for her when playing; he prefers independence. (F014)

Acceptance

Here, parents have shown distinct differences in the level of acceptance their siblings have towards the siblings with DD. It is not clear how far the siblings accepted their siblings' condition. According to the interviewees, the reaction from the siblings who do not have DD is mixed. For example, one mother stated, "My children find it difficult to accept their brother. They have asked me repeatedly to send him for adoption and place him on somebody's doorstep, which breaks my heart.*" (M017)*

The parent's perspective also plays a significant role in influencing their reaction to the situation they are facing. Out of the eight participants, six of them struggle to accept the situation, leading to feelings of confusion at various times. A father mentioned:

> Let alone my eldest son, I sometimes question myself: is he not talking, or has he purposely decided not to talk? My son used to call his younger brother 'the mute boy.' I can see that he loved and accepted him yet resented him for not being the kind of brother he wanted to have. Now my eldest son is still young, so I am not sure what he will feel tomorrow. (F020)

On the other hand, other siblings accept that children are different and adore them for who they are. In addition, they do their best to take care of them and support the children.

> My daughter, with the challenge, calls her elder brother 'Abba.' . . . He gives his life for her; he is a student still, yet he does everything he can. He does not let anyone mock or shame her. Seeing him accept his sister gives me peace of mind as well. (M009)

Especially with families that have more than two children, the level of acceptance also varies within the family depending on the family relationship. The personalities of the siblings, the parents' perspectives on the issue, and the mother's emotional burden all influence the family relation, which affects the acceptance.

Forbearance

When assessing how well children cope with their siblings, the success of their coping mechanisms depends on how effectively the situation is managed and the attitude of the children involved. Three parents noted that their children cope well, attributing this success to their patience and understanding in managing the situation. Two parents mentioned that it is not always easy to decide the level of coping, but one thing is certain. The level of patience and understanding that siblings show towards the child with DDs varies within the same family.

> Often, they tend to ignore him rather than try to understand what is going on with him. It can be frustrating for them if I ask them to check on him. Yet my youngest daughter, who is only 7 years old, is stepping up to take on responsibilities in caring for her brother. (M008)

Another mother shared, "I know he loves her, but when she makes a mistake, he hits her as punishment, claiming she did it on purpose. He doesn't even listen when I tell him to stop or not to hit her." (M009)

It is clear that each child's coping mechanisms and level of understanding differ. The girls tend to coax the children or ignore them totally, while the boys get physical or avoid the children with DD.

Exchanging Experience

None of the parents mentioned that their siblings desired to share their firsthand experiences with other siblings who have DDs. Additionally, none of the siblings described participating in special sibling meetings or having contact with siblings from other families who have a child with a disability. However, a couple of parents did mention that their children feel discomfort or a sense of loss when they are not able to spend time with their sibling who has DD.

The modeling behavior mentioned in these domains is another thing to note. Two siblings with DD tend to mimic the behavior of their older or typical siblings and try to take care of themselves.

> Our daughter expresses appreciation for the care provided by her parents and claims that it is her responsibility to assist her brother, who is challenged with ID. Now my kid, with DD, gradually begins to try to care for his younger twin siblings, imitating his sister by bringing shoes, assisting them in dressing up, and following in the footsteps of his elder sister. He may not do it properly, but he tries to do things. (M016)

This dynamic has positively affected the sibling with DD, as he also tries to support his younger brother to the best of his abilities. Yet, beyond modeling actions or behaviors, nothing emerged from the interviews showing experience sharing on a personal level.

Trust In Wellbeing

All parents underlined that while their siblings may struggle to accept having a sibling with a disability, none of them intended to cause pain or suffering to their siblings. One of the parents mentioned her experience as follows.

> My eldest son even wanted his sibling with DD to be at a facility, but he was distressed to see his brother with DD ill or in agony from a fall. He was frequently torn between his desire not to be burdened by his sibling and the worry that dominated his own sentiments. He once carried him to the clinic, running there; the boy became unwell, and my eldest son refused to wait for me to return. (M017)

Siblings are concerned about children with DD's incapacity to express their emotions while in pain or experiencing difficulties. One of the fathers shared the following in this connection.

> If my older son were to discover that his younger brother, who has autism, is unwell, he would become a nuisance by constantly urging us to take him to the clinic, fearing that his brother may be in great pain but unable to articulate his situation. (F020)

According to the parent, they leave their child with DD in their siblings' care when they face conditions that may necessitate their absence for several hours. The parents said that although the siblings without DD might be disappointed, they are sure the kids will be well after a while when they are away. The parents agreed that they never had any experience with children intentionally hurting their siblings with DD.

Social Support

Regarding social support and navigating the outside world, various experiences have been observed among siblings. Six parents reported that siblings without DD accompany their siblings to social gatherings and interact with friends, receiving appreciation and encouragement from their community. These siblings do not feel ashamed to be associated with their siblings with DD, as stressed by their father in the following quote.

> Her brother, even his older sister, does not feel ashamed for walking around with her. The neighbors or relatives might come to me and ask different questions about my daughters' situation. Yet never tried to target any of my children based on my daughter's disability, but rather encourages me. (F014)

Regardless of their personal feelings or thoughts towards their siblings with DD, neighbors and friends offer encouragement and appreciation when they try to support their siblings. One mother, for example, stated, *"*When attending various events with a child with developmental disabilities, the level of willingness varies between the oldest and youngest siblings. However, despite any initial hesitations, they consistently received encouragement and appreciation from neighbors, friends, and relatives.*" (M008)*

Dealing With the Outside World

Three parents noted their children intentionally avoid social situations that involve their sibling with DD, as they do not want to be identified in public settings. For instance, one parent (M021) shared that their son prefers to keep his relationship with his sibling with DD private, taking his friends to a different location to avoid being seen together. The rest of the parents, based on their reports, are not sure whether their children have experienced shame due to having a sibling with DD.

It is assumed that siblings do not mind their sibling's disability. However, one parent shared her experience as follows.

> .... It was a long time back. I noticed that my daughter felt ashamed of her brother. I used to accompany my son, who has autism, to pick her up from school. One day, I noticed she was trying to avoid him and asked me not to come with him. I explained to her that having a special brother makes her unique and that she should embrace and be proud of him. After our conversation, she stopped being embarrassed in front of others. (M022)

As parents mentioned, the impact of having a sibling with DD on other siblings can vary. ‘Some’ may embrace the uniqueness of their siblings, while others may struggle with social perceptions and choose to keep their relationship private.

Lifespan Siblings

Being siblings is a lifelong commitment, a relationship that requires effort from both parties. In the study, children’s demographic factors, such as age, sex, and birth order, are considered, but age is the most important. Yet, the superordinate “Lifespan Siblings” theme does not imply a longitudinal design; rather, it reflects parents’ descriptions of how sibling roles, responsibilities, and emotional responses differ across childhood and adolescence.

Age greatly influences the relationship between siblings. As children get older, the dynamics of the relationship shift to those of best friends, caretakers, parental figures, and sometimes even hostile neighbors. These subthemes are explored below.

Best Friends

All parents have noticed that children with DD tend to form stronger bonds and interact more with their younger siblings than with their older siblings. Parents have found that, regardless of birth order, it is easier for them to connect with the child who has DD. During this stage, the parents explained that these children spend more time together, share experiences, and show more patience towards each other, as clearly shown by one of the interviewees.

> Having four children has allowed me to see and understand the differences in their behaviors and relationships. My oldest child is 27 years old, my youngest is fifteen, and my son, who has autism, is twenty-three. I also have an 11-year-old niece living with us. As my children have grown, I have noticed a change in my son with autism's relationships with those who can communicate effectively with him. The older siblings have taken on a protective role, while my youngest daughter is struggling to connect with her brother. Currently, my son is closer to his cousin, who is younger, patient, and understanding towards him. (M022)

The differences in the child with DD may not be as obvious to the other siblings, and even if they do notice, it does not seem to significantly affect their relationships. In this connection, one mother stated, “The twins feel that their elder brother is not like other kids, even though they have no idea what is going on with him. But now, no matter what, they remain at his side.” (M016)

Caretaker - Parent Figures

As siblings without DD grow older, they may desire more privacy and distance from their siblings. As four of the parents mentioned, this shift in dynamics can lead the older siblings to take on a caretaker role, transitioning from a friendly sibling relationship to that of a caregiver or even an isolated parent. Additionally, age gaps among siblings can further complicate sibling relationships.

In some cases, the elder siblings may find themselves in a caretaker role, limiting their ability to interact with their sibling with DD on a peer level. This can result in a unique dynamic where the older sibling acts as a parental figure rather than a sibling. This experience was reported by most parents, as illustrated by the following quote.

> Despite my attempts to explain that he is her brother, she calls him ába'. She is content with this arrangement, and he also assumes the role of a father figure to her. He takes her for walks, feeds her, disciplines her, and buys her things. In my eyes, he has taken on the role of a father to her. (M 009)

Hostile Neighbor

As children grow older, they may try to establish their boundaries and assert their independence by being more aggressive, as four parents explained. Here, age and the children's point of view play a role, as shown in the following excerpt.

> If I leave my younger son with his older brother, he may not be able to leave the house to play. He would lock him inside. The older brother wants to distance himself from his younger brother, but he finds it difficult to do so. They were not like this when they were children. Somehow, he has changed as he has grown up. He is not acting like an older brother but more like an enemy. I know he loves his younger brother... but... (M021)

Some are bystanders who observe the gaps, challenges, and dynamics within a family but choose to remain detached and simply observe. These individuals prefer to keep their distance from the family dynamics they witness, as stated by one of the fathers.

> The boy shows a lack of concern for his sister. It seems like he does not care about what happens to her. For instance, he does not defend his sister when

> she gets into fights with the neighbor children. He just watches the situation unfold without getting involved. (F014)

Parental Involvement

Parental involvement is essential in fostering positive relationships among siblings. The role of parents is crucial in shaping how siblings interact with each other, the bonds they form, and the value they place on each other. Under parental involvement, we have four subtypes that could explain their involvement.

Understanding the Emotion

Understanding the emotions of siblings is key. Parents find it difficult to allow their children to express their frustrations and guide them in understanding their emotions. The parents struggle with this aspect. One mother expressed, “I do not like discussing emotions. I did not choose to have a child with Autism, and neither did the other siblings. We just have to continue." (M022)

To the parents, it is challenging to bring up topics related to having a sibling with DD. The participant expressed uncertainty about the sibling's thoughts and emotions regarding their sibling's condition.

> I do not know what he thinks or feels about having a sister with a disability. Even with the other older siblings, they are okay. I am mostly concerned about the mother, as she cries repeatedly for having such a child. As a family, we avoid discussing or dwelling on the situation with his sister. We strive to treat her like any other child. Whenever our son brings up our daughter's inability to speak, we reassure him that she will start talking when the time is right and leave it at that. (F014)

Emotions are a difficult topic in parents' hearts; so, they bottled up their emotions as well as those of their siblings, deflecting the siblings' emotional understanding towards the infinite abbey and leaving them alone to explore and find their own paths.

Knowledgeability

During the assessment or diagnosis, six out of the eight parents mentioned that they were not knowledgeable enough about their child's situation. This lack of understanding hinders the fostering of relationships among siblings, as parents are unsure of how to explain the situation, how to support each other as a family, or how to create a supportive and understanding environment for the entire family.

> I am unsure how to discuss with my son; it is a challenge for me. I know he loves her and will stop at nothing to make her happy. On the other hand, I feel powerless when he hits her. I do not know how to tell him that her behavior is 'normal to her reality' and that he should not hold expectations for her based only on her age. (M009)

The siblings are left in the dark about their brother or sister's situation. One of the parents has confided in me that she was unaware of what kind of problem her child has, let alone discussing it with the children.

> My children asked me why their sibling is different and why they are not as active as our cousin, who is the same age. I reassured them that it is okay to be different and that their sibling's situation is not that different from others. When they inquire about their sibling's grade in school, I provide them with a grade appropriate for their sibling's age. (M016)

The rest of the siblings know the name of the condition, but they have no idea of the severity of the disorder that their sibling is facing. This lack of understanding makes it challenging for the children to understand their sibling's situation.

Carrying the Yoke Alone

Four parents experience feelings of guilt and believe it is their sole responsibility to shoulder the burden alone. Each mother expressed that caring for a child with DD is their primary duty, leading them to unintentionally neglect the other children. The mother does not view it as neglecting her children; instead, they see it as putting in extra effort to care for them. Both fathers acknowledged their wife's dedication to caring for the children with DD with great diligence.

A married mother of four who decides to quit her job to take care of her son shares the following experienc.

> At times, I feel like I am the only one adjusting care for my child, essentially becoming a stay-at-home parent for the sake of my son. I face these challenges alone and wonder if we are destined to live like this. I put all my energy into taking care of him. . . this, on the other hand, makes the children who did not see the problem feel that they are not a priority. (M008)

However, parents fight for love by putting in effort caring for the sibling with DD. The two fathers mentioned that they actively take part in caregiving, which helps alleviate the burden on the mothers. Despite their differences, all parents agree on one thing: "As a family, we don't discuss."

> In our family, we do not talk about such matters. We simply live our lives and try to make things work. That is why I did not want to have another child, as it is already too much of a burden. I felt guilty; I think my effort in supporting my child with autism makes my other child bitter. (M021)

Parental Fairness

Five parents have expressed that the distribution of parental attention, resources, and expectations among their children is unfair, yet they believe they cannot do anything to amend that. One parent had explained,

> I mainly told my son that he needed to develop the strength to look after his brother if something happened to me or his father, but he does not react; instead, he stays silent and bemoans the fact that we have high expectations for him and not for his brother. (M021)

As the parents stated, siblings have raised issues about feeling neglected, not receiving desired items, and facing lofty expectations from their parents, especially when comparing themselves to siblings with DD. A mother (M016) shared that her children asked why she loved their sibling with DD more, to which she could only respond, "I loved him very much more than you guys". She struggled to find the right words to explain the situation to her children. In addition, she also noted the following.

> I make it a point to purchase something for him whenever possible. Despite the children not voicing their complaints often, the twins often gaze at me with resentment. In these moments, I remind them that I am the one who bought the items with my own money, to shift the mood. The girl, on the other hand, seems to come to terms with the situation and does not complain as often. (M016)

While three parents strive to balance their attention and resources fairly among their children, others find it challenging. Within the same family, some children are more understanding and willing to accept disappointment for the sake of their mother, while others show indifference.

> When I see all the kids, I do not put them on the same level. The oldest one tried to understand when I gave him the order to look after their younger brother, even though he was quite busy. My second boy, though he obeys to look after him when the situation is dire, has a short temper with him and does not want to sit with him for another second. And complained times and times about how I kept him away from class or from meeting his friends.

> Yet though the girl is the youngest, she is more modest and walks side by side with him in many things. (M008)

While the parents did not intend to show favoritism among their children, the unequal treatment created a perception among the children that their parents did not equally value them. This led to feelings of being less cared for in comparison to their siblings.

Here, in general, parental involvement functioned as a mediating influence on siblings’ quality of life. Parents’ emotional understanding, knowledge about disability, and efforts to balance attention shaped whether siblings experienced closeness, burden, or resentment. In this sense, parental involvement operated not as a single domain but as a relational mechanism influencing multiple quality-of-life domains simultaneously.

Discussion

The purpose of this study is to explore the quality of life of siblings who are growing up with a sibling with DD. We have identified three superordinate themes: the nine quality-of-life domains, lifespan siblings, and parental involvement, which contribute to overall quality of life. By analyzing parents' responses, we found a range of positive and negative experiences, highlighting the significant impact that having a sibling with DD can have on quality of life.

Using interpretative phenomenology (Willig, 2002), we have gained valuable insights into the life experiences of children who are raised alongside a sibling with DD, as reported by their parents. The parents' accounts have given us a deeper understanding of the challenges and rewards associated with living with a sibling who has DD, across various themes and subthemes.

Life domains of siblings

When looking at the nine domains of a sibling's quality of life - including joint activities, mutual understanding, private time, acceptance, forbearance, exchange of experiences, trust in well-being, social support, and navigating the outside world - we have discovered a range of unique experiences.

The nine domains of siblings' quality of life, as outlined by Moyson and Roeyers (2012) have been valuable in capturing siblings' perceptions. The findings of the current study align closely with those of Moyson and Roeyers (2012) and Luijkx et al. (2016), with siblings reporting a mix of positive and negative experiences stemming from having a sibling with DD. Having a sibling with DD can have both positive and negative effects on one's life. While there may be challenges, they are not always insurmountable. Growing up with a sibling who has a DD can affect the quality of life for other siblings in diverse ways.

The "trust in well-being" and "social support" domains were identified as the most often referenced positive aspects by siblings. The “mutual understanding” domain was more painted one-sided and relates to emotional maturity. These findings underscore the association of typical children taking on the responsibility to support and care for their siblings with DD. The study shows that ‘emotional understanding’ in sibling relationships varies significantly, often correlating with age and emotional maturity. Earlier studies have shown that younger siblings tend to show greater empathy and connection with their siblings with DD, while older siblings sometimes feel disappointed or confused about their siblings’ limitations. These mixed feelings can be worsened by a lack of parental guidance in navigating their sibling’s condition, suggesting that easing empathic connections is crucial for fostering healthier relationships (Floyd & Rinaldi, 2017). The participants' accounts highlighted that sibling relationships can fluctuate between protective roles and emotional disengagement, underscoring the need for interventions that foster understanding and emotional support among siblings (Forest & Elkins, 2018).

The social support provided injects positivity, ultimately enhancing the overall well-being of both siblings and their siblings with developmental disabilities. The parents explained that siblings without DD receive encouragement and support from their neighbors, relatives, and friends in any actions done for the benefit of the sibling with DD. This aligns with a study by Dervishaliaj et al. (2014), which showed that siblings' engagement received greater appreciation from others. Another study (Plumb & Kauffman,

2017) indicates that social support from peers and community members can significantly enhance siblings' emotional resilience. Participants expressed a sense of pride in their siblings with DD; others navigated feelings of embarrassment or discomfort in public contexts, reaffirming the need for increased community awareness and supportive initiatives to foster acceptance.

Age influences joint activities between siblings, as siblings without DD may drift apart as they get older. The sibling with DD is no longer on the same page, which severely limits joint activities between siblings as they grow older, particularly during the transition from childhood to adolescence. Eventually, the siblings will run out of things to do together, causing their relationship to evolve and potentially affecting the time they spend together. A study done by McHale & Gamble (2007) indicates that sibling interactions are more frequent and meaningful during childhood, with younger siblings showing more interest in engaging with a sibling with DD. As siblings grow older, their interests may change, leading to less participation in joint activities and affecting their relationship (Kenny, 2014; Niedbalski, 2024). Similar to the study done by Baker et al. (2015), insights from parents in the present study suggest that younger children, especially those below thirteen, tend to engage more in shared activities compared to older siblings, highlighting the impact of developmental changes on interaction dynamics. This shift is a natural progression and not necessarily negative. It is important to recognize that there may be differences between the activities siblings want to do together and what they can do. One study (Luijkx et al., 2016), for example, showed that children growing up with a sibling with DD have experiences similar to those without such a sibling with an age difference.

In contrast to Moyson and Roeyers' (2012) study, the parents in this research did not discuss siblings sharing their own experiences with other siblings who have DD. Instead, they observed that siblings with DD were looking up to their typical siblings as role models and learning from them. Parents have conflicting feelings about "acceptance," "forbearance," and "dealing with the outside world," possibly because there has not been enough discussion on the topic.

According to a study by Dervishaliaj et al. (2014), accepting their sibling's disability can be difficult for them. This is similar to findings in other studies that show siblings also struggle with accepting, forbearing, and dealing with the outside world. The study revealed that children who have a sibling with DD have private time to do things they enjoy, including being alone or spending time with friends. Similar to the study by Moyson and Roeyers (2012), the findings of this study indicate an emerging need for privacy and independence as siblings grow older, which aligns with existing literature suggesting that adolescents increasingly prioritize personal space and individual experiences over family interactions (Miller, 2011; Niedbalski, 2024). This shift can be perceived as a natural developmental response rather than as neglect, indicating the need to balance caregiving responsibilities and individual autonomy (Burgoyne, 2015).

The findings show a wide range of coping mechanisms employed by siblings, highlighting individual personality differences. Prior research has indicated that siblings with DD often elicit varying emotional responses and coping strategies, which can be influenced by familial dynamics (Giallo & Gavidia-Payne, 2006). The observed tendency for younger siblings to engage positively is encouraging; however, older siblings’ tendency toward avoidance or aggression underscores the need to teach effective coping strategies that promote patience and understanding (Vandell & Ramanan, 2016).

Sibling’s demographic factors

The study findings suggest that birth order and sex do not play a notable role in influencing the quality of life of children who have a sibling with DD, but age does. Yet, on forbearance, sex has been seen influencing how they respond to the child with DD. Research indicates that a child’s sex significantly influences how they engage with peers with DD, revealing distinct patterns in coping mechanisms and behavioral responses. Studies have shown that girls often adopt more nurturing strategies, such as coaxing facilitative communication when interacting with children with DD (e.g., Kuhlthau et al., 2005).

This behavior can be attributed to higher levels of empathy often associated with female children. It is suggested that girls are more likely to develop relational aggression strategies, which encompass nurturing behaviors aimed at fostering connection (Crick & Grotpeter, 1995). Therefore, girls may choose to engage with their peers with DD in ways that emphasize understanding and support, using verbal communication and emotional guidance to encourage participation. In contrast, boys often display more direct or physical responses towards children with DD, often using avoidance or aggression as their primary modes of interaction (Murray & Greenberg, 2000). This inclination towards physical response can be linked to gender norms that valorize assertiveness and dominance in boys' interactions. Boys are more likely to engage in physical play, which can sometimes manifest as exclusionary behavior towards children with DD or, on the contrary, as overly aggressive interactions. This divergence is illustrated by research that shows that boys may react to discomfort or unfamiliarity by withdrawing or engaging in physical activities that do not include all peers, particularly those with DD (McGowan, 2011).

Typically developing children show maturity progression as they age, while children with DD may have a different developmental trajectory, changing family dynamics, and the overall nature of the relationship among siblings. It is important to note the age-dependent nature of relationship dynamics, with siblings without DD potentially growing apart as they age and their interests diverge. Mulroy et al. (2008) point out that in families with a sibling with DD, other children may take on distinct roles based on their age at the time of the sibling's birth and how they respond to the situation. These roles can include being best friends, caretakers, parent figures, or hostile neighbors.

As noted in prior literature, sibling dynamics are not static; they often transform in response to life challenges and developmental changes (Hesketh et al., 2017). This study elucidates the notion that while siblings may initially enjoy deep connections, their relationships can shift dramatically as they each assume varying roles influenced by context and situational demands. The study done by Niedbalski (2024) demonstrates that the roles played by siblings are likely change over the course of a lifetime, which aligns with the current finding.

The way these roles are fulfilled within the family greatly affects the siblings' quality of life. It is important to understand that being different does not always lead to problems. Differences in personalities can help family members grow. A study conducted by Bachraz and Grace (2009) discusses the development of unique relationships between siblings. Change is not always negative, and taking on distinct roles as siblings grow can lead to a different kind of relationship, as long as it is not the ‘hostile neighbors.’

Parental involvement

The study emphasized the considerable role parents play in their siblings' quality of life. Four subthemes are identified: understanding emotions, knowledgeability, carrying the burden alone, and parental fairness. The study revealed that parents were less involved in these areas, which affected their quality of life for their children. It is essential to understand that differences among siblings do not always indicate problems; how we manage these differences is crucial. Bachraz and Grace (2009) suggested that allowing siblings to support each other in understanding a disability can promote friendliness and understanding. Providing proper responses, especially in terms of parental fairness, is important as siblings with DD may need more care. Sharing responsibilities can help parents find time to support the whole family.

The study indicates that families struggle with communication around developmental disorders, which can complicate emotional understanding and expression (Ramdass & Nokes, 2016). Parents’ feelings of guilt and overwhelming responsibility can inadvertently affect their children, fostering perceptions of inequality and neglect among siblings (Stein et al., 2019). Parents should have open and honest conversations with their children about their siblings' DD to promote understanding and acceptance within the family (Watson, 2004). The study confirmed that typical siblings ask their parents to understand their siblings with DD, while parents are hesitant to talk about DD and raise their awareness, leading to misunderstandings. By addressing their questions and concerns in a supportive way, parents can help their children navigate the challenges of having a sibling with DD (Williams et al., 2003). Balancing each theme of parental involvement is essential. Enhanced parental communication and community initiatives are needed to promote understanding and acceptance of developmental differences. Recognizing siblings as essential parts of the caregiving network can improve the quality of life for children with DD and their siblings.

Conclusion

This study explored parents' perspectives on their children's experiences with siblings who have developmental disabilities (DD). The analysis of the nine quality-of-life areas showed that age significantly affected private leisure and shared activities, with a noticeable decrease as the siblings got older. In contrast, gender was found to influence forbearance. Females are more likely to use persuasion and disdain, while men are more likely to use aggression and avoidance.

Growing up with a sibling who has DD was not described as wholly negative, yet it can present emotional and relational challenges for typical siblings. Understanding the specific limitations and needs of a sibling with DD helped foster empathy and resilience. Open discussion, emotional validation, and social support networks appeared as key factors in sustaining healthy relationships. Age has a significant impact on sibling relationships, more so than birth order or the number of siblings. As children grow older, their relationships with their siblings change, especially with a sibling with DD; they naturally evolve.

The quality of life for siblings was greatly affected by how their parents perceived things and how well they were able to deal with them. When parents demonstrated adequate understanding and emotional intelligence, the situation enabled them to both direct and understand their offspring, thus fostering a harmonious dynamic through the establishment of a nurturing environment. Conversely, the pressures and tensions experienced also influence the quality of sibling relationships. This, in turn, impacts the familial atmosphere, potentially heightening stress levels among siblings.

Implications for practice and policy

The study's results suggest that interventions targeting family members are necessary to improve the quality of life for typical siblings. Moreover, these interventions are related to the overall well-being of the family.

Family counseling, parental guidance, and structured follow-up services may help alleviate stress and strengthen relational functioning within the household. Supporting parents to have enhanced understanding and develop support and relations with both the typical and atypical children fosters an environment conducive to enhancing the quality of life of the siblings.

Policymakers may give prior attention to establishing a structured family support system. This system could provide families with access to counseling, medical consultancy, and coaching from various professionals to help assist and ensure a healthy and fulfilling quality of life. Additionally, community awareness programs may include reducing stigma and promoting inclusion. Moreover, policies that recognize and ease the difficulties faced by parents or caregivers of children with developmental disabilities could help create healthier family environments for everyone involved.

Direction for Future Research

Future research might explore intervention frameworks designed to support well-being across all family members. Further investigation benefits to focus on how specific therapeutic approaches can enhance familial bonds and promote sustained emotional health within families with children diagnosed with developmental disabilities. Moreover, examining the perspectives of siblings regarding their sibling with a developmental disability, alongside parental viewpoints, contributes to a more thorough comprehension of the resultant outcomes. Lastly, future studies may consider exploring how different developmental disabilities may differentially affect family quality of life, as well as how potential interventions can align with unique family structure and needs to enable tailored and context-sensitive support.

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