



Recollecting Adolescent Experiences of Individuals Having a Sibling with Down's Syndrome: A Qualitative Study

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Abstract

Adolescence is a crucial life stage marked by an individual's transition into adulthood. Contrary to those with typically developing siblings, individuals who have a sibling with Down Syndrome (DS) follow a unique trajectory of life experiences associated with their sibling's condition. Yet, this is an area unexplored in Sri Lankan scholarly research. The present study attempts to address this research gap by exploring adolescent experiences of having a sibling with DS; as recalled by adults. The study was conducted qualitatively, utilising semi-structured interviews. Data collected was analysed using thematic analysis. The sample consisted of six participants who were adults, had a sibling with Down Syndrome, and were fluent in English and/or Sinhala. Three main themes emerged addressing adolescent experiences attributed to the DS sibling, in terms of; the nature of the sibling relationship, family dynamics, challenges and coping with social support. Respective sub-themes highlight several details. Parents and siblings gradually adapted to the individual with DS, resulting in close familial relationships. Participants also illustrated how the sibling relationship shaped them as individuals. Parental differential treatment and future caregiving responsibilities were expressed as challenging, along with societal discrimination and stigmatization. However, social support through extended family and peers helped cope with such challenges. Conclusively, adolescent experiences of having a sibling with DS constitute both favourable and challenging aspects, influenced by many

individual-specific and environmental elements.

Keywords: Siblings; Down Syndrome; Adolescence

Introduction

Sibling relationships are one of the most enduring social bonds throughout an individual's lifetime. Consequently, their influence in shaping life experiences is indisputable (Conger & Little, 2010). Compared to those with typical development; siblings of those with special needs create an often-overlooked population with unique experiences and needs for support, which vary with the severity and specific diagnosis of the affected sibling, highlighting the need for disability-specific research. Down Syndrome (DS) is a prevalent, lifelong, genetic condition that impacts physical, mental and developmental domains (Bull, 2020). Therefore, familial care; and associated caregiving experiences differ from those of other disabilities. It is observable that most DS family-based research primarily relies on parental perspectives, increasing the compelling need to explore literature explicitly focusing on a sibling perspective. Siblings are an integral part of the family unit; they may take over the caregiving responsibilities from the parents once they reach adulthood. Therefore, it is notable that siblings navigate into their identities while mutually shaping each other's life journeys. This influence is particularly pronounced during adolescence; a period widely understood as critical and turbulent. Notably,

adolescents having siblings with DS have higher self-reported stress levels compared to those with typically developing siblings (Shivers et al., 2017). To develop supportive interventions for this population, there is a requirement to investigate the human experiences that underlie such results. Additionally, there is a lack of research involving adults recollecting their past experiences, which allows for a more comprehensive exploration that enables participants to illustrate and provide explanations as to how their experiences would have changed as they transitioned through various ages towards adulthood. Essentially, it enables individuals to view their memories from a broader lens and allows them to make previously unexplored connections in their experiences through recollection. Accordingly, this study attempts to explore these adolescent experiences of having a sibling with Down Syndrome; from the retrospective lens of adults recollecting their life stories; for the first time in Sri Lanka, according to the researchers' best-known knowledge.

There is a lack of Sri Lankan familial studies on caretaking DS individuals; let alone that of siblings. Accordingly, the existing literature on this topic is predominantly based on Western contexts. The current sibling-disability research base, including DS-specific literature, explores facets of the sibling experience such as; complexities of the diverse emotions experienced, responsibilities and roles assumed, nature of sibling and familial relationships, influence on later life, impact on other domains of life (Cooke, 2022; Kao et al., 2012; Stoneman, 2005; Strohm, 2008). While the existing research body tends to highlight the difficulties of having a sibling with a developmental disability, such as the psychological difficulties stemming from the internalisation of emotions (Marquis et al., 2019); other research explores positive aspects of the sibling experience such as the close bonds between siblings, and favourable influence on views and personalities (Lemoine & Schneider, 2022; Skotko et al., 2011). The present study consequently integrates a rather holistic perspective that encompasses examining

both challenging and transformative aspects of the sibling experience. This increases the scope of the present study as there is a lack of research that integrates both favourable and unfavourable aspects of the caretaking experience.

The present study aims to address these gaps by contributing to the understanding of this demographic in Sri Lankan contexts. Accordingly, the objective of this study is to; Explore adolescent experiences of having a sibling with DS; as recalled by adults. Further sub-objectives are: i) Investigating the challenges of having a sibling with DS during adolescence ii) Investigating favourable experiences of having a sibling with DS during adolescence iii) Exploring adults' perception of the adolescent relationship with their sibling with DS.

Materials and Methods

This study was conducted as a qualitative study utilizing semi-structured interviews. Purposive sampling was used as the sampling method; and the sample consisted of 6 Sri Lankan participants. Participants were between 18 to 45 years of age, had a sibling with Down syndrome, and were fluent in English and/or Sinhala. An interview guide was created targeting the research focus, with a few initial demographic questions. This study commenced once approval was granted by the pro-term ethics review committee, School of Psychology of SLIIT. Measures were taken to ensure confidentiality, and prevent harm and deception; with participation only, accessible once participants gave their informed consent.

Suitable participants were recruited through messages circulated on the researcher's social media. Once participants provided their informed consent to participate; the interviews were conducted online through Zoom; each lasting around 30-45 minutes, following the interview guide with suitable prompts and follow-up questions asked when necessary. Participants were given the freedom to have their cameras on or off. Once the interviews concluded,

participants received a debrief sheet, which included details of organizations providing free mental health services. Recorded interviews were transcribed verbatim by the researcher. Thematic analysis was utilised as the method of qualitative data analysis.

Results and Discussion

Thematic analysis revealed three main themes and several corresponding sub-themes: as shown below.

Table 1. Main themes and Sub-themes Emerged

Main Theme	Sub-Themes
Relationship with DS sibling	Intimate bond between siblings Conflict with DS sibling Transformative sibling connection Understanding and acceptance of DS condition
Family Dynamic	Evolving parental awareness of DS Harmonious family relationships Individual dynamics with other siblings Responsibilities and roles within the family
Challenges and Coping	Parental Differential Treatment Anticipating future responsibilities Discrimination and Stigmatization Coping through supportive networks

The sibling dyads' relationships were described as close, warm, with minimal conflicts; their bonds strengthened by cherished memories of their adolescence.

“But uh....but those small small things that we did

together, everything I think is quite memorable with him” (P3)

This aligns with the existing literature of DS sibling literature (Lemoine & Schneider, 2022; Skotko et al.,2011). Some participants even described the relationship with their DS sibling as impactful enough to optimistically shape their personalities and views of the world. Victor et al. (2021) suggest that smoother interactions with siblings led to an acceptance of the DS siblings and associated circumstances. In the present study, acceptance was concomitant with the participants' growing knowledge and understanding of their sibling's DS condition. This understanding was mainly built through external sources such as books and school lessons, in addition to consistent interactions with the sibling; with minimal influence from the parents, which contradicts existing literature (Graff et al.,2012). This discrepancy could be attributed to the fact that the parents also underwent a similar learning process to understand how to care for their child with DS; a finding of the present study, which reflects the lack of knowledge and potential difficulties accessing DS-specific information in an era of limited technological advancement.

Overall, it was noticeable that participants suggested that their families were tight-knit with close and warm relationships between family members. Those who had other typically developing siblings found companionship with them, based on the shared mutual familial experiences. Interestingly, contrary to research (Freitag et al., 2021; Skotko & Levine, 2006) most participants did not feel as if they were tasked with any major responsibilities or caretaking duties during their adolescence.

“My grandparents' house is nearby to the resource centre. So when I'm visiting them, I used to drop him there and go. But uh... I was not assigned any like, uh.... Strong responsibilities in the house”. (P5)

It is observed that participants generally regarded “caretaking” as only custodial care; however, literature conceptualises ‘caregiving’ to encompass

sibling guidance and emotional support as well. This may have led to the contradiction from existing literature. Additionally, domestic helpers were part of some participants' households, which may have contributed to the lack of perceived responsibilities. Next, participants suggested they were concerned about their future where they were expected to take responsibility for their DS sibling; consistent with existing research (Meltzer & Kramer, 2016). Further, all participants being female may have an underlying role in this finding, due to cultural gender roles and consequent expectations towards familial care. Another major challenge highlighted was the differential parental treatment towards them and their DS sibling, a finding consistent with research (Stoneman, 2005). Yet, the present findings suggest that most claimed no lasting hurt towards their parents for this, which could be attributed to cultural perspectives of filial piety. Further explanation for this perspective lies in the work of Liyanage (2017) who stated that familial caring for an individual with a disability, along with its associated experiences, is considered a social responsibility in Sri Lankan culture; potentially leading participants to be hesitant to express negative emotions stemming from their parents' actions; in fear of being perceived as 'complaining'. Additionally, they suggest that in Sri Lankan culture, disabilities are socially conceptualised in a "charity-based approach" where it is perceived as a result of sin, supporting segregation as 'normal' and 'abnormal' people. Such background social contexts can be observed in the findings of the present study; where stigmatization and discrimination experienced by families having a child with DS was highlighted by participants as a major challenge.

"But then, when I was schooling, I was not quite bullied, but people used to call me "that mandabuddika child's sister" (a derogatory term that translates to "retarded"). And uh...specially, there was this teacher, she used to always call me "mandabuddika child's sister", like that" (P6).

These aspects were rarely present in the current literature base; predominantly consisting of research from Western contexts, where there is a greater awareness and emphasis on disability inclusivity. Therefore, a potential newer finding of the present study contrasting the prominent scholarly notions, is spotlighted.

Despite several notable challenges faced by the participants during their adolescence, it was observed that participants and their families often depended on social support; especially with their peers. Interestingly, social support from extended family was also spotlighted. This is also a rather distinct finding of the present study, as the extended family is not emphasized in existing literature. Therefore, this can also be attributed to the possible cross-cultural differences between Western, individualistic cultures and the collectivist culture in regions such as South Asia; where the community, beyond the immediate family members, are of greater significance.

Accordingly, the themes and sub-themes presented highlights both favourable and challenging aspects of having a sibling with DS. These findings encompass not only the sibling relationship but also the family dynamic, building a broad picture of the adolescent experience of having a sibling with DS through the retrospective lens of adults. Thereby the research objectives have been reached, answering the research question.

Conclusions

Conclusively, the present study has presented how multifaceted dimensions shape both the favourable and unfavourable aspects of having a sibling with Down Syndrome during adolescence, through the lens of adults' recollections. Accordingly, this research observed how individual factors, DS-sibling-specific factors, familial dynamics, other social environments, and cultural factors intricately interplay into creating the full scope of recollected adolescent experiences. This understanding thereby spotlights the stories of this over-looked population in Sri Lanka.

There is a need for research with samples representing diverse demographics of both the participants and their DS siblings; as the participants of this study were all females, who were from English-speaking, urban backgrounds, mostly having brothers. Additionally, exploring the influence of gender roles and birth order on the experiences of having a DS sibling, across different cultural contexts could be a compelling avenue for further investigation. Additionally, research can also be conducted on the societal perceptions and attitudes on individuals with special needs, across rural and urban communities. Additionally, it is noteworthy that participants also mentioned experiences relating to their present adult life and childhood; however, these were excluded from the themes as the research only targets adolescent experiences. Overall, future studies could utilize diverse research designs to contribute towards a rich body of sibling-disability research, especially for Sri Lankan contexts.

Broadly, the insights gained through this study can be utilised in varied practical contexts, including clinical and therapeutic settings. Firstly, mental health providers can be armed with an increased understanding, while being equipped to facilitate the requirements of this population. Secondly, the findings of this study can contribute towards organizations that can support families caring for individuals with disabilities, in Sri Lanka. Furthermore, hospitals, schools, institutes for those with special needs, and governmental bodies can absorb new knowledge to identify shortcomings in the present systems and consequently improve services towards those with special needs and their families. Such initiatives could contribute towards increased societal awareness and lowered stigma, fostering a more inclusive and accepting society in Sri Lanka.

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