

Article

Study of feelings, perceived impact amongst siblings of down syndrome

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Abstract: Background: Down syndrome is a genetic disorder caused by the presence of an extra copy of chromosome 21. It is characterized by intellectual disability, developmental delays, and physical features such as a flattened face, short neck, and small head and ears. Previous research has suggested that having a sibling with Down syndrome may have a positive impact on children, as they may develop richer family values, warmth, kindness, and empathy. However, research on the needs and perceptions of siblings with Down syndrome in the Indian population is limited. Therefore, this study aims to assess the feelings and perceived impact among siblings of children with Down syndrome.

Methodology: From September 2015 to August 2016, 40 siblings of children with Down syndrome were recruited for this study, after obtaining written informed consent from both parents and siblings. Socio-demographic details were collected, and the siblings were interviewed using the "feeling and perceived impact questionnaire scale" to assess their feelings and perceived impact. Each sibling was interviewed only once.

Results: The majority of siblings, across all ages, expressed feelings of love or fondness towards their siblings with Down syndrome. A minority of siblings reported feeling sad or sorry for their sibling with Down syndrome. The majority of younger siblings enjoyed helping their sibling with Down syndrome learn new things.

Conclusion: The findings suggest that having a sibling with Down syndrome does not negatively impact the feelings or perceptions of siblings. Rather, siblings express positive emotions towards their brothers and sisters with Down syndrome, and enjoy helping them learn and grow. This study adds to the limited literature on the perceptions and needs of siblings of children with Down syndrome in the Indian population.

Keywords: Downs syndrome; Siblings; Brothers; Sisters; Feelings.

1. Introduction

Down syndrome, also known as trisomy 21, is a genetic disorder caused by the presence of all or part of a third copy of chromosome 21 [1]. This condition occurs in approximately one out of every 1000 babies born each year [2]. When a child is diagnosed with Down syndrome, his or her siblings become part of the disability community. Sibling relationships are unique in that they often last the longest of all human relationships and siblings typically share many common family experiences, including social and emotional intimacy. Therefore, the sibling relationship is significant to the development of a child [3]. The nature of sibling relationships has been shown to be influenced by family size, birth order, age difference, and gender association. Furthermore, previous research has frequently grouped siblings with varying disabilities together, making it difficult to appreciate the differing needs of distinct disabilities. Researchers have since called for a single-disability study design, and from such research, a preliminary understanding of what it is like to have a brother or sister with Down syndrome has emerged.

Some research suggests that having a sibling with Down syndrome may have benefits. Brothers and sisters experience a wide range of emotions, but typically, the positive feelings outweigh the negative ones. Current research supports the notion that siblings are more inclined to be positively impacted by a sibling with Down syndrome than to be adversely affected. Moreover, siblings find rich value in having a family member with Down syndrome, and most will assume positions of advocacy at some level in their lives [4]. Although the

literature on sibling impact has been noticeably slim [5], when siblings of individuals with Down syndrome were compared to matched controls, they reported more empathy and kindness toward their brothers and sisters and less conflict and more warmth in their relationships.

When siblings of individuals with Down syndrome were compared to those of individuals with autism, siblings of those with Down syndrome showed closer, warmer relationships, along with slightly better health, lower levels of depressive symptoms, and more contacts with siblings describing their sibling relationship as more positive and less likely to impact their relationship with their parents [6,7]. Additionally, brothers have been found to assume just as much responsibility as sisters when a sibling has Down syndrome [8]. Siblings of individuals with Down syndrome cope slightly better than family members of persons with other disabilities, a phenomenon known as the "Down syndrome advantage" [9].

It has been observed that siblings are able to effectively navigate the challenges that come with living with a child diagnosed with Down syndrome (DS), and demonstrate a remarkable ability to adapt to the situation. According to maternal reports, psychological and behavioral issues among siblings of children with DS are uncommon [10]. Moreover, siblings of children with DS have been reported to exhibit a higher level of admiration towards their sibling and demonstrate less conflict and competition in their relationships in comparison to typically developing siblings [11]. Despite the importance of understanding the needs and perceptions of siblings of individuals with DS, studies on this topic, particularly in the Indian population, are scarce. Therefore, the primary aim of this study is to assess the feelings and perceived impact of having a sibling with DS among a sample of siblings in India.

2. Materials and Methods

The study was conducted at the Paediatric Research Laboratory (PRL) of a tertiary care hospital following ethical clearance from the Institutional Ethics Committee. The cross-sectional observational study was conducted from September 2015 to August 2016, with a sample size of 40 siblings (brothers and sisters) aged 9-13 years of children with Down syndrome (DS) only, without physical or mental disabilities, and whose parents and siblings provided consent. Siblings below 9 years and above 13 years of age, having any other disability, and whose parents and siblings did not provide consent were excluded from the study. Informed written consent was obtained from both parent and child after providing a clear explanation of the study's nature and purpose. The study enrolled siblings of consecutive children attending the Paediatric Research Lab, and their socio-demographic information was collected using a case record form.

The "Feeling and Perceived Impact Questionnaire Scale" developed by Skotko et al. [12] was used to assess the siblings' feelings and perceived impact. The questionnaire included both quantitative and qualitative information, using a series of Likert statements and open-ended questions. For the younger siblings, the questionnaire used a 4-point Likert scale (ranging from "yes" to "no"), while the older siblings' questionnaire used a 7-point scale (ranging from "strongly agree" to "strongly disagree"). The questions assessed the siblings' feelings towards their brother or sister with DS and the perceived impact on their lives. The positive and negative constructs were identified as the summative scores from specific questions. Discriminant validity was achieved for both younger and older siblings' surveys, with correlation coefficients of -0.60 (N = 11) and -0.43 (N = 40), respectively [12]. A single interview was conducted for each sibling enrolled in the study.

3. Statistical Analysis

In this study, descriptive statistics were used to present the mean and standard deviation (SD) of continuous variables, while categorical variables were compared between two independent groups using percentage comparison. All statistical tests were two-tailed, with a significance level of $P < 0.05$. The analysis was conducted using Graphpad InStat version 3.0.

4. Results

4.1. Socio-demographic profile

4.1.1. Age

In our study, the age range of sibling participants who had a brother or sister with DS was from 9 to 13 years. The mean age of all sibling participants was 11.47 years with a standard deviation (SD) of 1.30 years. The youngest sibling participant was 9 years old, and the oldest sibling participant was 13 years old. The majority (70%) of sibling participants belonged to the preadolescence or preteen age group (i.e., less than 12 years of age), and 30% of participant siblings were in the adolescent/teen age group. Based on the different questionnaires and responses according to the age of participants, we created two age groups of 9-11 years and 12-13 years, with twenty participants in each group.

4.1.2. Gender

In our study population, we enrolled 20 male and 20 female siblings who had a brother or sister with DS, for a total of 40 participants. Of the DS siblings, 23 were male and 17 were female.

Majority of the participants (67.5%) were living in joint families, while 22.5% were in nuclear families and 10% were in extended families.

4.1.3. Socioeconomic status (as per revised parameters of Kuppaswamy's Socio- Economic Scale)

4.1.4. Type of Family

In our study, sibling participants were classified into various socioeconomic strata as per the revised economic parameters of Kuppaswamy's Socio-economic Scale [13]. Fifteen percent and 12.5% of participants belonged to the upper and upper-lower SES class, respectively. The majority of 40% and 32.5% of participants belonged to the upper-middle and lower-middle class, respectively

4.2. Feelings

4.2.1. Feelings from siblings age 9-11 years

Sibling participants in the age group of 9-11 years were asked to rate their level of agreement with statements about their feelings using a Likert scale of 1 to 4, with "1" indicating "Yes," "2" indicating "Most of the Time," "3" indicating "Once in a While," and "4" indicating "No." The percentage of siblings who circled "1" or "2" on the Likert scale were considered to have agreed with that respective statement. 90% of siblings expressed love and pride towards their brother or sister with DS, 70% expressed worry about their siblings with DS, and 45% expressed sadness about their brother or sister with DS. 20% of siblings felt embarrassed by their brother or sister with DS, 20% felt annoyed, and 10% wished they could trade their brother or sister with DS for one who does not have DS.

4.2.2. Feelings from siblings age 12-13 years

Siblings in the age group of 12-13 years were asked to rate their level of agreement with statements of feelings on a Likert scale ranging from 1 to 7, where "1" indicated "strongly disagree," "4" indicated "neutral," and "7" indicated "strongly agree." The percentage of siblings who circled "5," "6," or "7" on the Likert scale was considered as their agreement for that respective statement of feeling. All 100% of participants agreed that they liked their sibling with DS. Additionally, 90% of participants expressed a sense of pride regarding their siblings with DS and felt that their relationship with their sibling with DS was good. Also, 40% of participants felt sorry for their siblings with DS. A very small number of siblings (15%) felt embarrassed to have a brother or sister with DS, and 10% wished to trade their sibling with DS for a sibling without DS.

4.3. Perceived impact

4.3.1. Perceived impact from siblings age 9-11 years

Siblings in the age group of 9-11 years were asked to rate their level of agreement with statements about perceived impact on a Likert scale of 1 to 4, with "1" indicating "Yes," "2" being "Most of the Time," "3" being "Once in a While," and "4" indicating "No." The percentage of siblings who circled "1" or "2" on the Likert scale was considered their level of agreement for the respective statement of perceived impact. In our study, 90% of siblings thought that most of their friends found it fun to be with their siblings with DS. 90% felt that most of their friends were comfortable around their brother or sister with DS. 85% of siblings felt comfortable telling other people about their brother or sister with DS, and 85% agreed that they like to help their sibling with DS. 95% of participant siblings were comfortable asking questions about DS to their Mom or Dad. 40% of participants felt that their parents paid too much attention to their sibling with DS and not enough to them. 15% felt that their siblings with DS should have more chores to do.

4.3.2. Perceived impact from siblings age 12-13 years

Siblings in the age group of 12-13 years were asked to rate their level of agreement with statements of perceived impact on a Likert scale of 1 to 7, where "1" indicated "strongly disagree," "4" indicated "neutral," and "7" indicated "strongly agree." The percentage of siblings who circled "5," "6," or "7" on the Likert scale was considered to indicate agreement for that respective statement of perceived impact.

In our study, 85% of siblings felt that their friends were comfortable around their brother or sister with DS, and 95% felt comfortable asking questions about their siblings with DS. All of them agreed that they were better people because of their siblings with DS. Most of them (95%) planned to be involved with their brother or sister with DS when they become adults.

Among all siblings, 25% felt that their parents spent too much time with their sibling with DS, and 20% felt that they were often asked to do too much for their brother or sister with DS. Only a few (5%) felt that their social life was worse off due to having a brother or sister with DS

4.4. Positive and Negative construct for age group 9-13 years

For siblings of 9-13 years of age group survey, the constructs were identified as the summative scores from both feelings and perceived impact questionnaire as positive construct and negative construct.

In our study, majority of the participant siblings (92%) expressed positive feelings and perceived positive impact (high positive construct) and 7.5% had negative feelings and impact towards their sibling with DS (high negative construct).

4.5. Positive and Negative construct for age group 9-11 years

In our study, it was found that 85% of siblings in the age group of 9-11 years expressed positive feelings and impact towards their sibling with DS, with a mean of 1.52 and a standard deviation (SD) of 0.74. Only 10% of siblings had negative feelings and impact, with a mean of 3.16 and a SD of 0.69. The Pearson correlation test was used to examine the correlation between the positive and negative constructs. The Spearman's correlation coefficient was -0.8880, indicating a negative correlation between the positive and negative constructs. As the positive construct score increased, the negative construct score decreased, and this correlation was statistically significant ($P < 0.0001$).

4.6. Positive and negative construct for age group 12-13

In our study, for the age group of 12-13 years, all siblings (100%) showed a significant positive construct with a mean of 6.22 and SD of 0.86. Only 5% had a negative construct with a mean of 1.75 and SD of 1.34. A Pearson correlation test was used to find out the correlation between positive and negative constructs.

Spearman's $r = -0.6849$.

It was found that Spearman's r was negative, indicating that positive and negative constructs had a negative correlation. As the positive construct score increased, the negative construct score decreased, and this correlation was also statistically extremely significant ($P < 0.0009$).

Positive and negative constructs were compared among different age groups, genders, and birth orders. All the siblings (100%) in the 12-13 years age group and 85% of siblings in the 9-11 years age group had shown high positive feelings and impact towards their brother or sister with DS. 95% of sister siblings and 90% of brother siblings showed high positive construct towards their brother or sister with DS. Additionally, 96.25% of elder siblings and 85.71% of younger siblings expressed positive feelings and positive impact towards their brother or sister with DS. When negative construct was compared among different variables, only a few expressed negative feelings and impact towards their sibling with DS. The younger age group had shown higher negative construct than the older age group. No female or sister siblings expressed negative construct, while elder siblings had slightly more high negative construct than younger ones.

5. Discussion

5.1. Socio-demographic profile

In our study, we included 40 sibling participants with brothers or sisters who have DS, in the age group of 9-13 years. The majority of these siblings belonged to the pre-teen/preadolescent age group. We considered the age of the sibling participants as a factor that could affect the expression of feelings, impact, and adjustment to the stressful situation. Siblings' extensive contact and companionship during childhood and adolescence provide ample opportunities for them to shape each other's behavior and socioemotional development and adjustment. Several investigators have examined how sibling relationships change during early childhood [14] and during adulthood [15], but information about age trends during middle childhood and adolescence is scarce [16], with the few existing studies yielding discrepant findings.

We included an equal number of male and female sibling participants who had brothers or sisters with DS, considering the influence of gender dynamics over sibling relationships. The gender of the DS sibling patient also plays an important role in gender dynamics over their sibling relationship. In our study, 57.5% of DS patients were male, and 42.5% were female. This finding reflects that gender prevalence is higher in males than females in DS disease. This is similar to other studies, which report that the "Sex ratio in true Down syndrome is well known to be skewed towards males" [17]. A meta-analysis of publications reporting the cytogenetic profile of Down syndrome worldwide [18] showed a typical male prevalence among both patients with regular trisomy and carriers of translocation trisomy [19], either sporadic or inherited.

In our study, the majority of participants (67.5%) were living in joint families and 10% were living in extended families, while only a few were living in nuclear families. In India, for most people, their families are their primary support group. It is well known that good social support improves the ability to cope and modifies the occurrence of psychosocial stress or its consequences. This work also exemplifies how including siblings in research on families allows researchers to capture novel dynamics and illuminate how families operate as systems.

In our study, the majority of siblings belonged to the upper-middle and lower-middle socioeconomic status (SES) groups. This is likely due to the availability of free or minimally-priced services in municipal general hospitals where the study was conducted. Recently, SES has been considered an important source of health inequity, as there is a robust positive correlation between socioeconomic status and health.

5.2. Feelings of siblings towards their Brothers or Sisters with DS

In our study, the majority of brothers and sisters of all ages like their siblings with DS (Figures 1 & 2). All the sibling participants from the older age group, with no variation in gender difference and SES, agreed to the statement that they like their sibling with DS. Also, the majority of siblings (90%) from the 9-11 years age group expressed feelings of love towards their brother or sister with DS (Figures 1 & 2). The majority of siblings from both age groups are proud of their sibling with DS, with no significant variation in their gender and SES differences. Both older and younger brothers and sisters expressed feelings of pride towards their sibling with DS (Figures 1 & 2). Further, it is noted that differences in the age of the sibling were not associated with these feelings of admiration for their DS patient. Similar findings have been reported in a study done by Brian G. Skotko *et al.* in which they reported that "the vast majority of brothers and sisters love their siblings with DS and are proud of them" [12]. Also, similar findings have been reported in a sibling study of ASD as

"Siblings who have a brother or sister with an ASD reported admiration of their brother or sister and were satisfied with their relationship" [11].

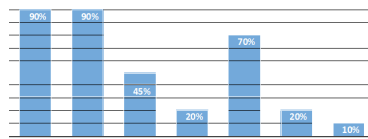


Figure 1. Feelings from siblings age 09-11 years

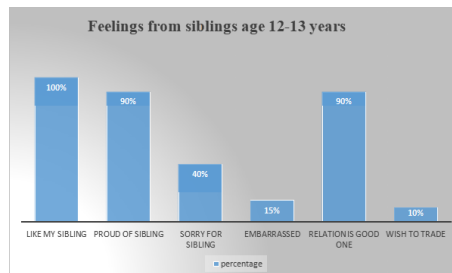


Figure 2. Feelings from siblings age 12-13 years

A minority of brothers and sisters said that they felt sad or sorry (45%) for their sibling with DS. The majority of them (70%) also tended to worry that their brother or sister with DS would be teased by others. Similar findings have been reported by Brian G. Skotko *et al.* study as "A minority of the surveyed siblings did feel sorry that their brother or sister had DS, particularly those whose siblings had significant learning disabilities. As many brothers and sisters now share the same school system with their siblings, one explanation could be that they felt bad about non-inclusive educational settings.

Amongst the youngest siblings, 20% said they were embarrassed about their DS sibling, while in the older group (15%) expressed feeling embarrassment of their DS sibling (Figures 1 & 2). These patterns are consistent with typical patterns within sibling relationships, but the feelings are likely to be more pronounced, we suspect, when the sibling with DS has behavioral issues. Despite some of these emotions, only a few (10%) brothers and sisters would ever want to trade their sibling with DS for a different sibling who did not have DS. A study by Meyer and Vadasy reported similar findings: "Additional concerns or stress on siblings of children with disabilities, including overidentification, embarrassment, guilt, isolation (loneliness & loss), resentment, and pressure to achieve" [19].

In our study, the majority (90%) of older siblings feel that their relationship with their brother or sister with DS is a good one. Younger siblings are sometimes (20%) annoyed that their brothers or sisters with DS might need more help to learn things (Figure 1). Yet, the majority of siblings (90%), of all ages, would not want to trade their brother or sister with DS for another sibling who did not have DS. Similar findings have been reported by a previous study done by Brian G. Skotko *et al.* [12].

5.3. Perceived Impact on Having Brother or Sister with DS

In our study, the majority (>85%) of siblings felt that their friends were 'comfortable' around their brothers/sisters with DS (Figures 3 & 4). The majority of younger siblings (85%) also felt 'comfortable' in telling other people that their brother/sister has DS. Similar findings were also reported by a previous study done by Brian G. Skotko *et al.* [12].

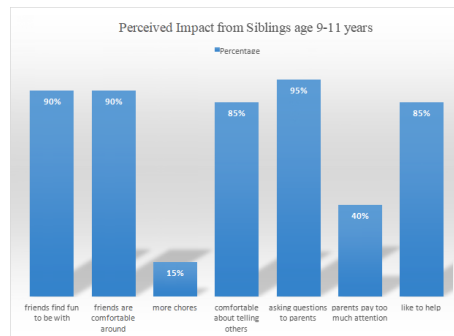


Figure 3. Perceived impact from sibling age 9-11 years

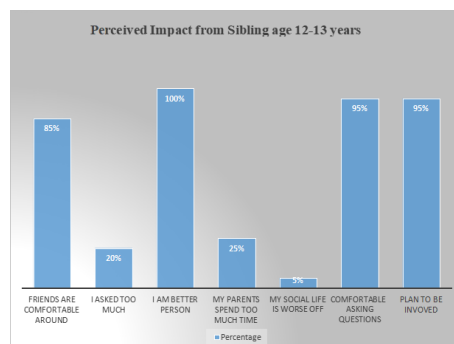


Figure 4. Perceived impact from sibling age 12-13 years

A minority of siblings (40%) felt that their parents paid too much 'attention' to their brother/sister with DS and not enough to them. Past research has reported that "isolation, loneliness, and loss are experienced when a parent spends more time with the child with a disability than with the sibling, or when the sibling is not educated and given the opportunity to discuss the disability, and when the sibling does not have peer support groups" [19]. However, a vast majority of all siblings (95%) felt 'comfortable' asking their parents questions about DS. Our findings are consistent with a previous study done by Brian G. Skotko *et al.* [12].

In our study, the majority of younger brothers and sisters enjoyed 'helping' their sibling with DS learn new things. For many, the experience is a positive, enriching one that teaches them to accept other people as they are. Similar findings were reported by the majority of past researchers. They have found that well siblings learn responsibility from an early age, and in some instances, they may have to adopt the caretaker role to their other siblings as well as their parents" [20].

In our study, a small percentage (15%) of younger siblings felt that their sibling with DS should be held accountable for more 'chores' around the house, and some felt burdened by the extra chores or caregiving responsibilities that they were asked to perform by their parents. A small percentage (20%) of older siblings also felt that they were asked to do too much for their brother/sister with DS. Very few (5%) older siblings felt that their social life was 'worse' off by having a brother/sister with DS. In general, all older brothers and sisters felt that they were better people because of their sibling with DS (Figure 4). As siblings matured, particularly as they entered high school and beyond, they began to identify themselves as better people because of their brother or sister with DS. Similar findings were reported by past research, specifically, "siblings may experience positive behaviour changes including greater maturity, empathy, and compassion. Regardless, the majority (95%) of older siblings also plan to be involved in their sibling's life when they both become adults. This feeling could be one of welcomed or resigned commitment. Similar findings were also reported by previous studies as "Siblings who reported higher levels of closeness tend to provide more support to their brother or sister with an intellectual disability in adulthood [7,21]. Siblings who have increased contact are more likely to plan to care for their brother or sister in the future" [22,23].

5.4. Positive & Negative Construct

Summative scores from positive feelings and positive perceived impact forms positive construct and similarly, negative feelings and negative perceived impact towards their siblings with DS form negative construct. In our study, the majority of sibling participants (92.5%) showed high positive constructs towards their sibling with DS, and only a few participants (7.5%) showed high negative feelings and perceived impact towards their sibling with DS. Among them, older siblings tended to show higher positive construct than younger siblings, with little differences in gender and birth order. A few younger siblings showed slightly higher negative construct than older ones. These scores of positive and negative constructs were mutually independent of each other. We found that some siblings had high scores on both constructs, while some did not score high on either of the scales. Similarly, many past studies reported that having a brother or sister with DS may have benefits, as siblings of persons with DS reported more empathy and kindness towards their brothers and sisters [5] and less conflict and more warmth in their relationships [24]. In comparison to having a sibling with autism, adult brothers and sisters of people with DS feel more understanding, trust, and respect for their siblings, describing their sibling relationship as more positive and less likely to impact their relationship with their parents [7,9]. In our study, no negative feelings or perceived impact were shown by sister siblings or females towards their brothers or sisters with DS. Similar findings were also seen in many past studies that found "sisters to have more favorable psychological outcomes than brothers" [25,26], (see Tables 11, 12, and 13.)

Table 1. Age group range

Range	Participant Sibling (n)	Mean	SD
9-13 Years	40	11.47	1.30

Table 2. Age group(years)

Age group (years)	Number of Participant sibling	% (n=40)
9-11	20	50
12-13	20	50

Table 3. Age in years

Age (Years)	Number of Participant sibling	% (n=40)
9	3	7.50
10	7	17.50
11	10	25
12	8	20
13	12	30
Total	40	100

Table 4. Gender

Gender of Participant sibling	Number	% (n=40)
Male	20	50
Female	20	50

Table 5. Gender of DS Patients

Gender of DS patient	Number	% (n=40)
Male	23	57.50
Female	17	42.50
Total	40	100

Table 6. Type of Family

Family type	Number of sibling participants	% (n=40)
Joint	27	67.5
Nuclear	09	22.5
Extended	04	10

Table 7. SES Class

SES class	Number of sibling participants	% (n=40)
Upper	6	15
Upper middle	16	40
Lower middle	13	32.5
Upper lower	05	12.5
Total	40	100

Table 8. Construct-wise

	Number of participant siblings	% (n=40)
Positive construct	37	92.5
Negative construct	3	7.5

Table 9. Positive construct

	Number of siblings who having high construct	% (n=20)	Mean	Median	SD
Positive construct	17	85	1.52	1.25	0.74

Table 10. Negative construct

	Number of siblings who having high construct	% (n=20)	Mean	Median	SD
Negative construct	2	10	3.16	3.25	0.69

Table 11. Positive construct who having high construct

	Number of siblings who having high construct	% N=20	Mean	Median	SD
Positive Construct	20	100	6.22	6.5	0.86

Table 12. Negative construct who having high construct

	Number of siblings who having high construct	% N=20	Mean	Median	SD
Negative Construct	1	5	1.75	1	1.34

Table 13. Descriptive Statistics

Variables	groups	Total (n)	Number of siblings who having high Positive construct	% of siblings for Positive construct (n=total)	Number of siblings who having high Negative construct	% of siblings for Negative construct (n=total)
Age	9-11years	20	17	85	2	10
	12-13years	20	20	100	1	5
Gender	Male	20	18	90	3	15
	Female	20	19	95	0	-
Birth order	Elder	26	25	96.25	2	7.69
	Younger	14	12	85.71	1	7.14

6. Conclusion

This was a cross-sectional observational study of feelings, perceived impact, and coping strategies among siblings of Down syndrome patients in a tertiary care hospital. The aim of the study was to collect socio-demographic details among siblings of DS patients. Socio-demographic data were collected using a case record form, while feelings and perceived impact were assessed using a structured questionnaire scale. Data from 40 siblings were analyzed, and findings from this research highlight the differences in experiences based on birth order, age, and other developmental factors. From the study, it was concluded that no negative feelings or perceived impact were shown by siblings towards their brothers or sisters with DS. The majority of them had high positive construct towards their siblings with DS. Although there were certain limitations, such as a small sample size, the study could be extended with a larger sample size. Also, due to the stringent inclusion and exclusion criteria, the results cannot be generalized to all siblings of DS in the general population.

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Conflicts of Interest: The authors declare no conflict of interest.

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