

ORIGINAL RESEARCH

## Studying of coping strategies amongst the siblings of downs syndrome

Sanjay Ghuge

Assistant Professor, Department of Psychiatry, Prakash Institute of Medical Sciences & Research, Islampur Dist- Sangli, India.

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### ABSTRACT

**Introduction:** Downs Syndrome(DS) is also known as trisomy 21. It is a genetic disorder which results in delayed physical and mental growth, along with some typical physical features like flat and wide face, protruding tongue, short neck, small chin etc. If supported with proper love and care, people with DS can live happy and healthy life. According to some research, having a brother or sister with DS has many benefits. Brothers or sisters of the DS children experience many emotions, but mostly the positive ones. Siblings of brothers/sisters with Down syndrome showed closer, warmer sibling relationships, along with slightly better health, lower levels of depressive symptoms as compared to siblings of the children with autism. Research on coping strategies amongst the siblings of DS are very few in the Indian population. Hence, in this research, we wish to study the coping strategies amongst the siblings of the Downs Syndrome. **Methodology:** Ethical clearance from the Institutional ethics committee was taken before beginning of the study. The study was conducted on siblings of children with DS and the duration of the study was from September 2015 to August 2016. All parents and children have been explained about the nature of study and its application. Siblings of consecutive children attending the Paediatric research lab and satisfying the inclusion and exclusion criteria were enrolled for study. 40 participants were included for the study. The Coping mechanisms used by siblings were assessed by using the 'CHILDREN'S COPING STRATEGIES CHECKLIST REVISION 1 SCALE'. Each sibling had to go through interview. **Result:** In our study, it is found that majority of siblings (87.5%) used active and support seeking' coping strategies while minority of them (27.5%) used distraction and avoidant coping strategies. **Conclusion:** Although most siblings were found to switch between styles, they were each found to have a predominant style of coping. Some of Siblings were found to engage in both problem-focused as well as avoidant/distraction coping strategies.

**Keywords:** Siblings, coping strategy, DS, active, support seeking

**Corresponding Author:** Dr. Sanjay Ghuge, Assistant Professor, Department of Psychiatry, Prakash Institute of Medical Sciences & Research, Islampur Dist- Sangli, India.

**Email:** [sanjay101284@gmail.com](mailto:sanjay101284@gmail.com)

### INTRODUCTION

Down syndrome(DS) is one of the most common chromosome abnormalities in humans. It is also known as trisomy 21, is a genetic disorder caused by the presence of all, or part of a third copy of chromosome 21.<sup>1</sup> Typically associated with physical growth delays, some of its characteristics are typical facial features such as small chin, slanted eyes, poor muscle tone, a

flat nasal bridge, a single crease of the palm, and a protruding tongue due to a small mouth and relatively large tongue,<sup>2</sup> along-with mild to moderate intellectual disability.<sup>3</sup> DS was named after the physician John Langdon Down, who in 1866 published a description of patient he identified as “Mongolian”.<sup>4</sup> There is no cure for Down syndrome.<sup>5</sup> Education and proper care have been shown to improve quality of life. Some children with Down syndrome are educated in typical school classes, while others require more specialized education. Some individuals with Down syndrome graduate from high school and a few attend post-secondary education. Life expectancy is around 50 to 60 years in the developed world with proper health care. Brothers and sisters influence each other and play important role in each other’s lives. Indeed, sibling relationships make up a child’s first social network and are the basis for his or her interactions with people outside the family. Although each family is unique, an experience like the birth of a child with Down syndrome brings the need for adaptation and reactions that resemble between some families. In studies where children with DS are compared to children with other disabilities, researchers have noted a “Down syndrome advantage”: their families are described as warmer, closer, and more harmonious<sup>6,7</sup> their parents experience less stress<sup>8,7,9</sup> and fewer cases of depression<sup>9</sup> their mothers and fathers are more confident about their parenting skills<sup>10</sup> and claim that their children are easier to raise<sup>11</sup> with more satisfying networks of support<sup>9</sup> their parents experience less overall pessimism<sup>6,9</sup> and report more positive experiences<sup>8</sup> with fewer time restrictions.<sup>12</sup> Some projects that are developed with families of people with Down syndrome have shown promise for improving the quality of life of families, offering informational and emotional support, but also directly support the autonomy and independence of individuals with this condition.<sup>13</sup> Those with typical development reported qualities, such as his brother with Down syndrome be: affectionate, communicative, cheerful and companion. These data corroborate the study of Mayer<sup>14</sup> with mothers’ speeches to describe their children with Down syndrome as loving and cheerful. It was also pointed out by the four participating behaviours of hyperactivity and tantrum. These results demonstrate that, according to most participants, the interaction with the brother with Down syndrome is very good. When they are together, they establish an interaction with affection, companionship, protection and care for the brother. Sibling adjustment did not appear to be related to the behaviour problems of the children with developmental disabilities over a time.<sup>15</sup> Siblings are successful in dealing with the challenges of living with a child with DS and adapt well. Some studies also reported, there were both positive as well as negative consequences with adapting to sibling with DS.<sup>16</sup> Siblings of children with Down syndrome suggested great admiration for their sibling and less competition in their relationships when compared to normally developing comparison children.<sup>17</sup> Research on coping strategies amongst the siblings of DS are very few in the Indian population. Hence, in this research, we will assess the coping strategies amongst the siblings of the Down Syndrome.

## **MATERIALS AND METHODS**

This Cross-sectional observational study was conducted after getting the necessary ethical permissions from the Ethical committee of the tertiary care hospital. The study was conducted at the Paediatric research laboratory (PRL) of tertiary care hospital and the duration of the study was from September 2015 to August 2016. The sample size included for the study was 40 patients. Siblings without physical and mental disability, having (brothers and sisters) aged 9-13 years of children with DS only, and whose parents and siblings are willing to give consent were included in the study. Whereas, siblings below 9 years & above 13 years of age, having any other disability and whose parents and siblings refrained from giving consent were excluded from the study. The nature of the study and its application was explained to all the parents and children respectively. Written informed consent was taken

from the parents and children in their local language. The Coping mechanisms used by siblings were assessed by using the ‘CHILDREN’S COPING STRATEGIES CHECKLIST REVISION 1 SCALE’.

### Children’s coping strategies checklist revision 1 (CCSCR 1) scale:<sup>18</sup>

The CCSCR-R is a dispositional coping measure, it asks children about the coping strategies they generally used when faced with a problem in the past month. This scale has 4 major factors as Active coping strategies, Distraction strategies, Avoiding strategies and Support seeking strategies. Each major factor is further divided into subscale/dimensions. The Active Coping Strategies dimension has two sub-classifications as ‘Problem focused coping’ and ‘Positive cognitive reconstructing’. Problem focused coping further has 3 subscale as Cognitive decision making(CDM), Direct problem solving(DPS), Seeking understanding(SU) and Positive cognitive restricting has 3 subscales as Positive focus(POS), Optimism(OPT), Control(CON). Distraction strategies having Premature release of emotion(PRE), and Distraction action(DA), while Avoidant strategies includes Avoidant actions(AVA), Repression(REP), Wishful thinking(WISH) as subscales. Support seeking coping strategies includes Support for actions(SUPA) and Support for feeling(SUPF) as subscales. Each subscale has 4-5 questions. Each question is scored as 1 to 4 scale, as 1 means never and 4 means most of the time.

Single interview has been arranged for every participant in the study.

### Statistical Analysis

After the data collection, non-parametric tests were used for statistical analysis. All tests were two tailed, with statistical significance set at  $P < 0.05$ . Overall group comparisons were performed on continuous variables with Mann-Whitney U test to test difference in means of two independent groups. Graph pad Instat version 3.0. was used for analysis.

## RESULTS

### I) Coping strategies used by participants age group 9-13 years

Table 1

Coping strategies	Number of siblings who used	% (n=40)	Mean	SD
Active coping	35	87.5	2.93	0.54
Distraction coping	11	27.5	1.90	0.62
Avoidant coping	11	27.5	1.71	0.65
Support seeking	35	87.5	87.50	0.62

In our study, majority number of siblings (87.5%) used active and support seeking strategies. 27.5% siblings used distraction and avoidant coping strategies.

### 1] Active coping strategies

Mann-Whitney U test was used to compare active coping between 2 variables.

Table 2

Variables	Groups	Total	Number of siblings who preferred	%	Mean	SD	median	P value
Age	9-11 years	20	18	90	2.99	0.55	3.25	0.2898
	12-13 years	20	17	85	2.86	0.53	3.04	

<b>Gender</b>	Male	20	16	80	2.78	0.60	2.99	0.1219
	Female	20	19	95	3.08	0.45	3.16	
<b>Birth order</b>	Elder	26	24	92.30	3.04	0.45	3.16	0.1429
	Younger	14	11	78.57	2.71	0.64	2,66	

In this study, when active coping strategies were compared in between the age groups, 90% siblings from 9-11 years of age group and 85% from 12-13 years of age group used active coping strategies with P value of 0.2898, with no statistically significance. 95% females or sister siblings and 80% male or brother sibling participants used active coping and P value was 0.1219, which was statistically non- significant. Also, 92.30% elder siblings and 78.57% younger siblings used active coping strategies with P value of 0.1429, considered statistically non-significant difference by Man Whitney test. That is majority siblings of from each age group, gender and birth order had used active coping strategies with no statistically significant differences in between them.

## 2] Distraction coping strategies

Mann-Whitney U test was used to compare active coping between 2 groups

**Table 3**

<b>Variables</b>	<b>Groups</b>	<b>Total</b>	<b>Numberof siblings who preferred</b>	<b>%</b>	<b>Mean</b>	<b>SD</b>	<b>median</b>	<b>P value</b>
<b>Age</b>	9-11years	20	6	30	1.92	0.63	1.66	0.8914
	12-13years	20	5	25	1.88	0.62	1.66	
<b>Gender</b>	Male	20	8	40	2.08	0.66	1.78	0.0675
	Female	20	3	15	1.72	0.63	1.55	
<b>Birth order</b>	Elder	26	4	15.38	1.72	0.54	1.55	0.0078*
	Younger	14	7	50	2.23	0.62	2.23	

\*P value is statistically significant

In our study, when distraction coping strategies were compared in between the age groups 30% siblings from 9-11 years of age group and 25% from 12-13 years of age group used distraction coping strategies and P value was 0.8914. 15% females or sister siblings and 40% male or brother siblings used distraction coping and P value was 0.0675, which was not quite significant. Also, 15.38% elder siblings and 50% younger siblings used distraction strategies withP value was 0.0078, considered statistically significant difference by Mann-Whitney test. That is younger siblings used more distraction strategies than elder ones.

## 3] Avoidant coping strategies

Mann-Whitney U test was used to compare active coping between 2 group

**Table 4**

<b>Variables</b>	<b>Groups</b>	<b>Total</b>	<b>Numberof siblings who preferred</b>	<b>%</b>	<b>Mean</b>	<b>SD</b>	<b>median</b>	<b>P value</b>
<b>Age</b>	9-11years	20	6	30	1.83	0.70	1.50	0.1764
	12-13years	20	5	25	1.60	0.60	1.32	

<b>Gender</b>	Male	20	8	40	1.88	0.74	1.67	0.2242
	Female	20	3	15	1.55	0.52	1.33	
<b>Birth order</b>	Elder	26	4	15.38	1.55	0.55	1.33	0.0691
	Younger	14	7	50	2.03	0.74	2	

In our study, when Avoidant coping strategies were compared in between the age group 30% siblings from 9-11 years of age group and 25% from 12-13 years of age group used Avoidant coping strategies and P value was 0.1764. 15% females or sister siblings and 40% male or brother sibling used Avoidant coping and P value was 0.2242. Also, 15.38% elder siblings and 50% younger siblings used avoidant coping strategies with P value of 0.0691 by Mann-Whitney test. Only a few siblings from each age group, gender and birth order had used Avoidant coping strategies with no statistically significant differences in between them.

#### 4]Support seeking coping strategies

Mann-Whitney U test was used to compare active coping between 2 groups

**Table 5**

Variables	Groups	Total (N)	Number of siblings who preferred	%	Mean	SD	median	P value
<b>Age</b>	9-11years	20	16	80	2.83	0.68	3.05	0.1521
	12-13years	20	19	95	3.10	0.53	3.33	
<b>Gender</b>	Male	20	16	80	2.72	0.66	2.94	0.0126*
	Female	20	19	95	3.22	0.48	3.33	
<b>Birth order</b>	Elder	26	23	88.46	3.13	0.56	3.33	0.0206*
	Younger	14	12	85.71	2.66	0.61	2.66	

\*P value is statistically significant

When Support seeking, coping strategies were compared in between the age group 80% participate from 9-11 years of age group and 95% from 12-13 years of age group used Support seeking coping strategies with P value of 0.1521, which was statistically non-significant. 95% females or sister siblings and 80% male or brother sibling participants used Support seeking coping and P value was 0.0126, which was considered statistically significant. Also, 88.46% elder siblings and 85.71% younger siblings used same strategies with P value of 0.0206, which was considered statistically significant difference by Mann-Whitney test. That is female or sister sibling seeks more support coping strategies than male or brother siblings to any stress. Also, younger siblings seek more support coping strategies than elder ones.

## DISCUSSION

Coping can be defined as the thoughts and behavior some individual uses to manage internal and external demands of situations that are appraised as stressful. There is overwhelming evidence that families of children with DS experience higher levels of stress than families with nondisabled children.<sup>19</sup> Till date only few researches have assessed siblings coping strategies of DS patients. We assessed four-factor model of coping style, which consists of active, distraction, avoidance, and support-seeking strategies, provided a good fit for the assessment of situation-specific coping. In our study, it is found that majority of siblings (87.5%) used active and support seeking coping strategies while minority of them (27.5%) used distraction and avoidant coping strategies. Andrea M. et al. studied Coping in Parents and Siblings of Adolescent Cancer Survivors reported similar finding as "Siblings who were older used more active coping, and the longer it had been since their brother or sister was

diagnosed, the less avoidant coping they used”.<sup>20</sup> Active coping strategies includes problem focused and positive cognitive restructuring strategies. Active coping included strategies in which the child focused on the stressful event, either to change the situation or to think about it more positively. Problem- focused coping is an adaptive coping strategy that involves engaging in behaviours that targets problematic issues directly. In our study, majority (87.5%) of siblings had used active coping strategies with no significant differences in their age, gender and birth order. Orsmond et al. study on adult with DS shown “they used more problem coping strategies and also, identified problem-focused coping strategies as one key factor associated with closer sibling bonds”.<sup>21</sup> Similarly, support seeking coping strategies were used by majority of these siblings of all ages. It was seen that majority of them were significantly sister siblings and elder ones who preferred support seeking coping strategies over the brother sibling and younger ones. The central feature of the support-seeking dimension is the use of social support in coping, both to solve problems and to reduce negative emotions. One study reported that sisters of females with DS typically engaged in emotion-focused coping instead of problem-focused coping.<sup>21</sup> In avoidance, siblings may be seen avoiding stressful situations cognitively, physically or both. This type of coping is hypothesized to protect siblings from negative emotions related to physical interaction with or thinking about issues involving the disabled sibling.<sup>22</sup> In our study, it is also seen that minority (27.5%) of them had used distraction and avoidant coping strategies to cope with their day-to-day stress, with no significant differences in their age or gender. Significant difference has been noted where younger siblings preferred more distraction coping strategies over the elder siblings. Although most siblings were found to switch between styles, they were each found to have a predominant style of coping. Some of siblings were found to engage in both problem-focused as well as avoidant/distraction coping strategies.

## CONCLUSION

This was a cross sectional observational study of coping strategies amongst siblings of Down syndrome patients in a tertiary care hospital. coping strategies were assessed by using Children coping strategies checklist revision 1 scale. Data of 40 siblings was analysed by using Graphpad Instat version 3.0.

Majority of siblings (87.5%) used ‘active’ and ‘support seeking’ coping strategies while only a few of them (27.5%) used ‘distraction’ and ‘avoidant’ coping strategies to cope with the stress. Majority (87.5%) of siblings had used active coping strategies with no significant differences in their age, gender and birth order. Similarly, support seeking coping strategies were used by majority of these siblings of all ages. It was seen that majority of them were significantly sister siblings and elder ones who preferred high support seeking coping strategies over the brother sibling participant and younger siblings. Minority (27.5%) of them had used distraction and avoidant coping strategies to cope with their day-to-day stress, with no significant differences in their age or gender.

So from the above observation we can conclude that, significant difference has been noted where younger siblings preferred high distraction coping strategies over the elder siblings. Maladaptive patterns of coping may be addressed by teaching sibling s how to identify stressors and cope with them more effectively. Siblings have been found to engage in trial and error method of coping. They can be given opportunities to practice problem-solving skills that will prepare them for better coping in future.

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