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Assessment of Sense of Coherence among parents of children with Down Syndrome and Intellectual Disability and their perception of their child's oral health

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ABSTRACT

Aim: Sense of Coherence (SoC) explains why some individuals cope up with extremely stressful life conditions and stay healthy, while others become ill and diseased. The present study was carried out to assess the SoC in parents of children with Down Syndrome and intellectual disability and whether it has any impact on their perception of maintaining the oral health of their children.

Material and method: The present study was conducted at various special schools in Bangalore. The study group consisted of parents of 30 children with Down Syndrome (Group I) and parents of 30 intellectually disabled children (Group II). Parents of 30 healthy children (Group I) formed the control group. All the children were aged between 10 and 15 years. Items in the SoC questionnaire were rated on a seven-point Likert scale, where participants were asked to understand each question and mark their response by circling one of the numbers from 1 to 7. The items were scored accordingly and the mean SoC score was calculated for each group using one-way analysis of variance test. Pairwise comparison of mean SoC was done between the groups using Tukey's HSD post-hoc analysis. Significance was considered at $p < 0.05$.

Parents in each group were also asked to respond to a questionnaire comprising 22 questions, including demographic details, behavioral and attitudinal variables regarding oral hygiene practice of the child and caregiver, their dietary preference, and reason to visit a dental clinic. The groups were then compared for the variables using Chi-square test and $p < 0.05$ was considered as significant.

Results: The mean SoC value was 53.0 ± 12.0 for parents of Down Syndrome children and 52.3 ± 10.6 for parents of intellectually disabled children. Parents of healthy children had a mean SoC value of 81.0 ± 3.3. The low SoC values seen among parents had a negative impact on their perception of their child's oral health.

Conclusion: The mean SoC was found to be significantly low among parents of children with Down Syndrome and intellectual disability which had a negative impact on their perception of maintaining the good oral hygiene of their children.

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Sense of coherence; stress, Down Syndrome; intellectual disability, oral health

Introduction

Caring for a child with a developmental disability imposes several physical, financial, and emotional demands on parents. In comparison to parents of children without disabilities, parents of children with a developmental disability tend to report poorer subjective wellbeing and are at risk of physical and mental health problems, such as high-stress levels and clinical depression [1]. The most significant sources of stress experienced by parents of these children are: permanency of the condition, disapproval for the child's behavior demonstrated by the society and family members, and insufficient professional support [2]. The birth of a child with disabilities increases the probability of stress in the parents. However, it does not affect every parent in the same way. What makes a stimulus stressful depends to some extent on characteristics of the

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person exposed to it. It takes both the stressful stimulus condition and a vulnerable person to generate a stress reaction [3]. It was found that mothers experienced more stress associated with their child's low degree of self-sufficiency, behavior problems, and physical development than did fathers. Stress experienced by parents may significantly affect their adjustment to taking care of a child with special needs. Successful adaptation depends, among other things, on how parents cope with stress [2].

Aaron Antonovsky introduced his salutogenic theory "Sense of Coherence (SoC)" as a global orientation to view the world and the individual environment as comprehensible, manageable and meaningful, claiming that the way people view their life has a positive influence on their health [4,5]. The term "salutogenesis" originates from the Latin word "*salus*" meaning health and the Greek word "*genesis*" meaning origins [4]. The three elements, such as comprehensibility (cognitive), manageability (instrumental/behavioral), and meaningfulness (motivational), formed the concept of this theory [6]. Antonovsky emphasizes that the SoC concept is a disposable orientation rather than a personality trait/type or coping strategy. The SoC construct reflects a person's capacity to respond to stressful situations [7].

The salutogenetic perspective proposed by Antonovsky (1987) suggests that it is impossible to foresee what consequences a specific stressor has on an individual's health without knowing something about that person's view of her/himself and the world. Instead of focusing on the stressors per se, Antonovsky focused on personality factors which contribute to health [3]. He suggested that individuals can be located on a continuum with endpoints of health-ease and health-disease and any phenomenon that facilitates movement towards the health-ease end of the continuum is viewed as a generalized resistant resource, examples being money, ego, strength, or social support [4,5]. These resistant resources contribute to making the stressors understandable to the individual who encounters them. The cumulative experience of coming to an understanding of these stressors will, over time, create a strong SoC in the individual [3]. According to Antonovsky, persons with a strong SoC are more likely to define a possible stressful event or situation as a nonstressor, and it can be assumed that they can adapt to the demand, than persons with a weak SoC. The person with a strong SoC is likely to appraise a stressor as happier, less contentious, or less dangerous than one with a weak SoC.

According to Antonovsky, stressors can be either chronic or acute. Chronic and acute stressors have different relations to SoC. Acute stressors or major life events are discrete and time-limited. The death of a family member, divorce, or the birth of a new family member are examples of an acute stressor. In these situations, individual differences in SoC levels are predictive of individual differences in health outcomes. A person with a strong SoC will be better equipped to handle stressors in a health-preserving way. A person with a weak SoC will be more vulnerable and the event is more likely to have a harmful effect on that individual's health [5]. The birth of a child with disabilities or the realization that the child has a developmental disability can be characterized as an acute stressor, and the SoC of the parent prior to birth of the child may determine whether or not this experience will be a threat to the health and well-being of the parent [3].

In some cases, an acute stressor can alter a person's life such that it becomes a chronic stressor. A chronic stressor is a generalized and long-lasting life situation, condition, or characteristic that is built into the life situation of the person. Chronic stressors are thought to have a potentially negative impact on an individual's SoC level. The acute stressor of learning that one's child has a developmental disability can be transformed with time into the chronic stress of parenting a child with special needs. If parenting a child with special needs can contribute to experiences of chronic stress, then these parents are at risk of developing low SoC levels [7]. A strong association between higher SoC and lower incidence of chronic diseases and better quality of life has been reported in several studies [8–12]. In the field of oral health, the incidence of chronic oral diseases such as dental caries and periodontitis is not only related to biological factors but may also be influenced by non-biological factors such as oral health behaviors [13]. An individual's behavior is the manifestation of several determinants such as psychosocial and environmental factors that can be influenced by the SOC concept. This concept is considered as a practical model emphasizing the psychosocial aspect of oral health promotion rather than the risk of the disease [5].

SoC has been considered as a psychosocial determinant of oral health behaviors in adults [14]. Individuals who have a stronger SoC are more intended to attend regular dental check-ups, clean their teeth more often, and have healthier dietary habits as compared to their counterparts who have lower levels of SoC [15]. The responsibility of the

child's health usually belongs to the child's parents, and decisions regarding the child's health are also taken by their parents. A child's oral health and related behaviors are influenced by their caregiver's oral health-related knowledge, behavior, and attitudes [16]. The oral health perceptions, as well as oral health-related quality of life (OHRQoL) of both children and adolescents, are significantly affected by their parents' SoC [17,18].

There are very few reports on SoC of parents with disabled children, and Indian studies are lacking. Hence, the aim of the present study was to assess SoC among parents of children with Down Syndrome and parents of children with intellectual disability as well as its impact on the ability to maintain their child's oral health as compared to parents of children without disabilities. The null hypothesis was that the SoC of parents and its impact on the ability to maintain their child's oral health would be similar among all the three groups.

Methodology

Parents of 30 children with Down Syndrome (Group I) and parents of 30 children with intellectual disability (Group II), aged 10–15 years participated in the study. Parents of children with Down Syndrome were recruited from a school for special children, Divya Downs Development Trust, Bangalore. Parents of children with intellectual disability were recruited from Arpana Special School, Bangalore. Prior permission was obtained from the authorities of the educational institutions followed by written informed consent from each parent. Ethical clearance was also obtained from the Institutional Ethics Review Board. The control group consisted of parents of 30 randomly selected healthy children with no signs of mental disability (Group III), of similar age and gender. Parents of children having autism or cardiovascular disorder along with Down Syndrome and parents who were unwilling to participate were excluded from the study.

The demographic characteristics of the three groups were recorded. All the participants belonged to the socio-economic status of the lower middle class and resided in the city of Bengaluru.

Aaron Antonovsky's Swedish version of the short Sense of Coherence (SoC) scale (13 items) was used to record the sense of coherence [5].

The items in the SoC questionnaire were divided into three sub-scales such as Comprehensibility (C), Manageability (MA), and Meaningfulness (ME) and each item was attributed to any one sub-scale (Table 1). Items were rated on a seven-point Likert scale, where participants were asked to understand each question and mark their response by circling one of the numbers from 1 to 7.

The score for a sub-scale and the total score for SoC as a whole was calculated by adding the points marked for each item in the questionnaire. Some of the items in the questionnaire were positively scored whereas others are negatively scored. The items with reverse scoring included 1–3, 7, and

Table 1. Items included in the SoC scale (13 items).

Sl. no	Items to record SoC	Sub-scale
1	Do you have the feeling that you don't really care about what goes on around you?	ME
2	Are you surprised by the behavior of people whom you thought you knew well?	C
3	Has it happened that people whom you counted on have disappointed you?	MA
4	Until now your life has had: no clear goals or very clear goals?	ME
5	Do you have the feeling that you are being treated unfairly?	MA
6	Do you have the feeling that you are in an unfamiliar situation and don't know what to do?	C
7	Doing things you do every day is: A source of deep pleasure and satisfaction or a source of pain and boredom?	ME
8	Do you have very mixed up feelings and ideas?	C
9	Does it happen that you have feelings inside which you would rather not feel?	C
10	Many people—even those with a strong character—sometimes feel like losers in certain situations. How often do you feel this way?	MA
11	When something happened, have you generally found that: You overestimated or underestimated its importance or you saw things in the correct proportion?	C
12	How often do you have the feeling that there's little meaning in the things you do in your daily life?	ME
13	How often do you have feelings that you're not sure you can keep under control?	MA

10. If the item was positively scored, then the rating value marked was taken at face value and if the item was reverse-scored, the lowest value marked was taken as the highest value.

The items were scored accordingly and the mean SoC score was calculated for each group using one-way analysis of variance test and $p < 0.05$ was considered as significant. Pairwise comparison of mean SoC was done between the groups using Tukey's HSD post-hoc analysis. Significance was considered at $p < 0.05$.

Median SoC score for a total of 90 individuals (three groups) was calculated in order to categorize the individuals as: low-SoC and high-SoC groups. The low- and high-SoC groups were compared among the three groups using the chi-square test and $p < 0.005$ was considered as significant.

Parents in each group were also asked to respond to a questionnaire comprising 22 questions, including demographic details, behavioral and attitudinal variables regarding oral hygiene practice of the child and caregiver, their dietary preference, and visit to a dental clinic. The groups were then compared for the variables using Chi-square test and $p < 0.05$ was considered as significant.

Results

A significantly lesser number of fathers of children with intellectual disabilities were graduates ($p < 0.05$) (Table 2). There was a significant difference between the three groups with regard to the education level of the father. A significant number of children with intellectual disabilities had single parents.

A significantly higher percentage of children with Down Syndrome brushed their teeth under parental supervision and about 16% of the children with intellectual disabilities did not follow any oral hygiene practice. Supervision of tooth brushing was followed only by parents of children with Down Syndrome. More than 60% of children in both the study groups practiced tooth brushing once a day. Parents of all the three groups expressed financial problem as a reason for not seeking dental care. Another impediment for seeking dental care in the study groups was the inability of children to express themselves. Frequency of consuming sweets twice daily was seen among children with Down Syndrome and the control group. Mean SoC value was found to be higher in the parents of children in the control group than those of the two study groups. A significantly higher percentage of parents of children with Down Syndrome and intellectual disability had a low SoC (≤61) (Table 6).

Discussion

The severe behavioral disturbances and lack of social competence and responsiveness seen in children with disabilities have been found to increase parental stress. For parents of children with Down

Table 2. Demographic characteristics of study groups.

Sl.no.	Variable	Category	Group I *n* (%)	Group II *n* (%)	Group III *n* (%)	χ^2 value	*p*-value
1	Gender	Male	15 (50.0)	21 (70.0)	15 (50.0)	3.258	0.20
		Female	15 (50.0)	9 (30.0)	15 (50.0)		
2.	Siblings	Single Child	5 (16.7)	5 (16.7)	2 (6.7)	1.731	0.87
		Child with sibling	25 (83.3)	25 (83.3)	28 (93.3)		
3.	Caregiver	Father	0 (0.0)	1 (3.3)	0 (0.0)	2.087	0.72
		Mother	8 (26.7)	7 (23.3)	8 (26.7)		
		Both	22 (73.3)	22 (73.3)	22 (73.3)		
4.	Marital status of caregiver	Married	26 (86.7)	21 (70)	29 (96.7)	8.289	0.02*
		Single	4 (13.3)	9 (30)	1 (3.3)		
5.	Level of mother's education	≤Higher secondary	18 (60)	19 (63.3)	19 (63.3)	0.095	0.95
		≥Graduation	12 (40)	11 (36.7)	11 (36.7)		
6.	Level of father's education	≤Higher secondary	9 (30)	19 (63.3)	9 (30)	8.465	0.01*
		≥Graduation	21(70) 21(70)	11 (36.7)	21(70)		
7.	Employment status	Employed		19 (63.3)	25 (83.3)	3.102	0.21
		Unemployed	9 (30)	11 (36.7)	5 (16.7)		

*$p < 0.05$ is significant.

Syndrome and intellectual disability, the acute stressor of knowing that their child has a disability can have a negative impact. Parenting a child with special needs has more impact on the life situations and psychological health of parents with increasing risk of experiencing threats to all of the central concepts of SoC, i.e., comprehensibility, manageability, and meaningfulness. These three dimensions of SoC could be used as a framework to explore the impact of a child's disability on parents and to guide the implementation of methods of intervention. For instance, comprehensibility refers to the extent to which events are perceived as making sense. Addressing this dimension would focus on parents' information needs regarding their child's condition, the services available to them, and parents' accounts of their experiences. Meaningfulness involves a sense that challenges faced are worthwhile. Parents could be encouraged to explore their perceptions of their child's disability and their reactions to the challenges they face. Antonovsky's definition of manageability encompasses the ability to use coping strategies flexibly. High stress caused by difficult child behavior, in combination with restrictions in pursuing personal interests and goals in life, may be factors that contribute to a higher risk of low SoC in such parents. Therefore, this study was undertaken to assess Sense of Coherence of parents of children with Down Syndrome and parents of children with intellectual disability as well as its impact on the ability to maintain their child's oral health as compared to parents of children without disabilities. The impact on parents of having a child with a developmental disability is pervasive. The Swedish version of the short SoC scale was used in this study so as to limit the number of questions in an otherwise rather extensive survey. Limiting the number of items has been thought to increase the response rate. The SoC-13 has shown good psychometric properties in previous studies [3]. It has been reported to have a test–retest reliability of 0.52–0.97 and an excellent internal consistency of 0.74–0.91 [6,7].

In the present study, a questionnaire comprising 22 questions was designed to record the demographic details, behavioral and attitudinal variables regarding oral hygiene practice of the child and the caregiver, their dietary preference, and visit to a dental clinic and were compared among the three groups.

Demographic characteristics and oral health practices

The demographic characteristics showed that almost all the children in all the three groups had siblings, hence exclusive care could not be provided by parents as in case of those who were a single child. Although more than 50% of mothers in all the three groups had an indistinguishable educational status which was less than or equal to higher secondary, a higher percentage of children in the study groups were not taken to a dentist in the past (Table 2). In developing countries like India, where finance plays a pivotal role, the existing ailment in the child takes precedence over oral health care due to the lack of access to government hospitals and the financial hindrance in seeking private dental care, especially among those belonging to the lower middle class socio-economic status as in the present study.

Reason for dental visit

Dental caries continues to be the most prevalent oral disease in children and hence was the main reason for making a dental visit. As observed with parents of special children, dental pain was the most common cause for seeking dental care (Table 3). Irregular alignment of teeth and esthetics were a matter of concern only among parents of children without disabilities, whereas a high incidence of rapid, destructive periodontal disease experienced by children with Down Syndrome was a prior concern among parents. This may be related to the presence of a high level of inflammatory cytokines and many other known factors which play an important regulatory role in their immune responses [19].

Oral health awareness of parents and children

In the present study, oral health awareness of parents of children with Down Syndrome was greater than that of parents in the other two groups. This could be due to the regular dental camps that were held in their school premises and periodic interaction of the dentist with the parents regarding oral health including oral hygiene and diet. A dental visit, especially to a private practice may not be affordable and was regarded as a major impediment for seeking dental care by all parents. Moreover, parents of special children are already burdened with additional medical expenses and hospital visits that the importance given to oral health issues is minimal.

Oral health practices of parents and children

Around 80%–93% of children showed increased preference for sweets in the present study

Table 3. Variables associated with oral health practices of children.

Sl.no.	Variable	Category	Group I *n* (%)	Group II *n* (%)	Group III *n* (%)	χ^2 value	*p*-value
1.	Dental visit	Not taken to a dentist in the past	9 (30)	15 (50)	2 (6.7)	13.738	0.001*
		Taken to a dentist in the past	21 (70)	15 (50)	28 (93.3)		
2.	Reason for dental visit:	Tooth Decay	14 (66.7)	9 (60)	13 (46.4)	14.486	0.07
		Deposits/stain on teeth	5 (23.7)	0 (0.0)	3 (10.7)		
		Pain	0 (0.0)	5 (33.3)	9 (32.2)		
		Spacing/ Proclined teeth	1 (4.8)	1 (6.7)	3 (10.7)		
		Bleeding gums	1 (4.8)	0 (0.0)	0 (0.0)		
3.	Frequency of dental visit	Every 3 months	0 (0.0)	0 (0.0)	3 (10.7)	16.066	0.01*
		Every 6 months	1(4.8)	0 (0.0)	6 (21.4)		
		Once a year	1(4.8)	5 (33.3)	4 (14.3)		
		Only when in pain	19 (90.4)	10 (66.7)	15 (53.6)		
4.	Oral hygiene practice	Brush their teeth	29 (96.7)	25 (83.3)	30 (100)	7.500	0.03*
		Don't brush their teeth	1 (3.3)	5 (16.7)	0 (0.0)		
		Brush on their own	12 (41.4)	20 (80.0)	30 (100)	26.918	<0.001*
		Brush under supervision	17 (58.6)	5 (20.0)	0 (0.0)		
5.	Frequency of tooth brushing	Once daily	20 (69.0)	15 (60.0)	9 (30.0)	10.324	0.04*
		Twice daily	8 (27.6)	9 (36.0)	20 (66.7)		
		Thrice daily	0 (0.0)	0 (0.0)	0 (0.0)		
		After each meal	1 (3.4)	1 (4.0)	1 (3.3)		
6.	Obstacles faced when seeking dental care	Transportation	4 (13.3)	2 (6.7)	7 (23.3)	16.031	0.04*
		Lack of awareness	3 (10)	8 (26.7)	8 (26.7)		
		Financial problem	11 (36.7)	10 (33.3)	14 (46.7)		
		Inability of child to express	10 (33.3)	8 (26.7)	0 (0.0)		
		Debilitating illness	2 (6.7)	2 (6.7)	1 (3.3)		
7.	Preference for sweetened food	Prefer	24 (80.0)	26 (86.7)	28 (93.3)	2.308	0.32
		Does not prefer	6 (20.0)	4 (13.3)	2 (6.7)		
8.	Frequency of consumption	Once daily	8 (33.3)	22 (84.6)	10 (35.7)	17.624	0.002*
		Twice daily	14 (58.3)	3 (11.5)	16 (57.2)		
		With every meal	2 (8.4)	1 (3.9)	2 (7.1)		

*$p < 0.05$ is significant.

(Table 3). In Indian families, there is a socio-cultural practice of including sweetened food in their routine diet. The availability of sweets, confectionaries, and bakery products is so ample that parents as well as other family members frequently indulge in giving sweets to children. In addition, parents of special children may use sweetened foodstuffs to cajole or comfort their child.

Mean sense of coherence

Intergroup comparison of the mean sense of coherence was found to be significant (Table 5). The weaker SoC scores seen in parents of children with Down Syndrome and children with intellectual disability indicate that their perception of life in general is affected and can have an influence on their coping ability towards stressful situations.

Conclusion

The significantly low SoC scores seen among parents of children with Down Syndrome and children with intellectual disability (Table 4) have implications on parents' ability to cope effectively, not only with the stresses related to caring for their child with a disability but also with stressful life events

Table 4. Comparison of mean sense of coherence.

Groups	*N*	Mean ± SD	*p*-value
Group I	30	53.0 ± 12.0	<0.001*
Group II	30	52.3 ± 10.6	
Group III	30	81.0 ± 3.3	

*$p < 0.05$ is significant.

Table 5. Pairwise comparison of mean SoC.

Group	Group	Mean difference	95% CI of the diff		*p*-value
			Lower	Upper	
Group I	Group II	0.7	−5.1	6.5	0.95
	Group III	−27.9	−33.7	−22.1	<0.001*
Group II	Group III	−28.7	−34.5	−22.9	<0.001*

*$p < 0.05$ is significant.

Table 6. Comparison of sense of coherence between the three study groups.

Groups	Low SoC(≤61)	High SoC(>61)	χ^2 value	*p*-value
	n (%)	*n* (%)		
Group I	22 (73.3)	8 (26.7)	45.067	<0.001*
Group II	23 (76.7)	7 (23.3)		
Group III	0 (0)	30 (100.0)		

*$p < 0.05$ is significant.

in general. This in turn had a negative impact on their perception to maintain their child's oral health, thus affecting the oral health practices of children.

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Author Query

Please provide expansion for the abbreviation "HSD."

PARENTS PERCEPTION ON THEIR CHILD'S ORAL HEALTH—A QUESTIONNAIRE

1. What is the gender of your child?
   i. Male
   ii. Female
2. Is your child a single child?
   i. Yes
   ii. No
3. Who is the caregiver?
   i. Father
   ii. Mother
   iii. Both
4. Marital status of caregiver
   i. Married
   ii. Single
5. Caregiver's daily tooth brushing frequency
   i. Once & less
   ii. Twice & more
6. Caregiver's frequency of sugar intake
   i. < once/day
   ii. > = once/day
7. Education of mother
   i. < = Higher secondary
   ii. > = Graduation
8. Education of father
   i. < = Higher secondary
   ii. > = Graduation
9. Caregiver's occupation
   i. Unemployed
   ii. Employed
10. Is good dental health important for optimum general health?
    i. Yes
    ii. No
11. Have you taken your child to a dentist
    i. Yes
    ii. No
12. If yes, for what reason?
    i. Tooth decay
    ii. Deposits/stain on teeth
    iii. Pain
    iv. Spacing/proclination of teeth
    v. Bleeding from gums
13. How often do you think your child should visit-the dentist?
    i. Every 3 months
    ii. Every 6 months
    iii. Once a year
    iv. Only when in pain
14. Does your child brush his/her teeth?
    i. Yes
    ii. No
15. How does your child brush his/her teeth?
    i. Alone
    ii. Under supervision
    iii. Other
16. What do you use to clean your child's teeth?
    i. Toothpaste
    ii. Toothpowder

iii. Neem stick

iv. Activated charcoal from rice husk

v. Does not clean

17. What should be the frequency of tooth brushing?

i. Once daily

ii. Twice daily

iii. Thrice daily

iv. After each meal

18. Do you clean your child's tongue?

i. Yes

ii. No

19. Do you think it is necessary to fill your child's decayed teeth?

i. Yes

ii. No

20. What do you think are the obstacles you face as a parent in providing dental care for your child?

i. Transportation

ii. Lack of awareness

iii. Financial problem

iv. Inability of child to express

v. Debilitating illness

21. Does your child like to consume sugary food?

i. Yes

ii. No

22. If yes, how often does your child consume sugary food?

i. Once daily

ii. Twice daily

iii. With every meal