Cardiology in the Young (2010), **20**, 538–546
doi:10.1017/S1047951110000685

Original Article

Sense of coherence in adolescents with congenital cardiac disease

Kaori Nio

College of Nursing, Aichi Medical University, Nagakute, Aichi, Japan

Abstract This study aimed to identify the influence of illness cognition and background factors on the sense of coherence among junior high school and high school students with congenital cardiac disease. We conducted an examination using the illness cognition scale and sense-of-coherence scale, and verified the reliability and validity of both. Participants were 172 students with congenital cardiac disease and 295 healthy students, who were 12–18 years old. The relationship among sense of coherence, basic and disease-related attributes, and illness cognition in healthy adolescents and those with congenital cardiac disease was investigated. Sense of coherence was higher in boys than in girls and higher in junior high students than in high school students. Adolescents with congenital cardiac disease scored higher for sense of coherence than healthy students. Those who scored lower on the illness cognition scale for "hardships resulting from restrictions and limitations for illness", "the desire to be understood by others", "anxieties about the state of the disease and possibility of death", or "not wanting people to know of one's disease" showed higher sense of coherence than those who had higher scores for these elements.

Keywords: Transition to adulthood; illness cognition; illness experience; independence; school life

Received: 16 October 2009; Accepted: 28 March 2010; First published online: 2 June 2010

In Japan, the life convalescence of children with congenital cardiac disease has improved remarkably. Hence, there are thought to be more than 400,000 adults living with congenital cardiac disease, and this number is increasing by an estimated 5% per year.[1,2] However, this means that the number of children with physical disability resulting from congenital cardiac disease is also increasing, and these children experience difficulties in school and social life. For adult patients with congenital cardiac disease, social independence is a major issue.

Congenital cardiac disease is present from birth. Therefore, patients have encountered stress related to the disease from childhood. Moreover, they have to keep dealing with such stress through their lives.

The present study of adolescents with congenital cardiac disease focuses on the sense of coherence and also on illness cognition, which influences the way in which patients manage their lives and cope with treatment.

Sense of coherence is a concept based on the theory of salutogenesis. It explains why people in stressful situations stay well and are even able to flourish.[3] It can be thought of as the ability to cope with stressors or the ability to keep one's health. It is composed of three elements: comprehensibility, manageability, and meaningfulness. Comprehensibility: a belief that things happen in an orderly and predictable fashion and a sense that you can understand events in your life and reasonably predict what will happen in the future. Manageability: a belief that you have the skills or ability, the support, the help, or the resources necessary to take care of things, and that things are manageable and within your control. Meaningfulness: a belief that things in life are interesting and a source of satisfaction, that things are really worth it, and that there is good reason or purpose to care about what

Correspondence to: K. Nio, Aichi Medical University, College of Nursing, Nagakute-cho, Aichi-gun, Aichi-ken, 480-1195, Japan. Tel: +81 561 62 3311 (ext. 3351); Fax: +81 561 63 1093; E-mail: kaorinio@aichi-med-u.ac.jp

happens. Sense of coherence is formed by positive human experiences and can be reinforced by the successful experience of processing stress.

Illness cognition is a person's perception of the consequences of a disease and their beliefs about that disease. Illness cognition in adolescents with congenital cardiac disease has six components: (a) hardships resulting from restrictions and limitations of illness; (b) positive acceptance of one's illness; (c) the desire to be understood by others; (d) anxieties about the state of the disease and possibility of death; (e) not wanting people to know of one's disease; and (f) not wanting to take a burden on one's body. Participants with more severe conditions score higher in (a), (c), (d), and (f) than those with milder conditions, whereas high school students score higher than junior high school students in (c) and (f).[4]

This study aimed to identify the influence of background factors and illness cognition on the sense of coherence in junior high school and high school students with congenital cardiac disease. The broader aim was to identify methods of support for strengthening the sense of coherence.

Participants and methods

Participants

Participants comprised junior high school and high school students with congenital cardiac disease, adolescents with congenital cardiac disease (n = 534), and without congenital cardiac disease, healthy adolescents (n = 406), aged 12–18 years.

Data collection

The study was conducted in 2006. The following data were collected:

- Basic attributes: Age, school year, and sex.
- Disease-related attributes: Type of congenital cardiac disease, presence and type of cyanosis, comorbidities, medication use, number of hospitalisations, number of operations, classification on the school life management guidance list, and ability to take part in physical education.
- Sense of coherence: This was measured using the Japanese version of the 13-item Sense of Coherence Questionnaire for children; the reliability and validity of this questionnaire have been demonstrated.[5] Permission for use was granted by the creator of the questionnaire. This questionnaire consists of 13 items applicable to children. It was developed based on two scales. One of them is age-adopted sense of coherence scale by Torsheim,[6] which was modified from the sense of coherence-13 for adults developed by Antonovsky.[3] The other is a Japanese 29-item version for the elementary school upper grades modified by Hayashi,[6] which was made from the sense of coherence-29 for adults developed by Antonovsky.[7] It was translated into Japanese with some changes in phrasing related to the cultural context. Accuracy of the translation was confirmed by testing the questionnaire on a junior high school student who had English as their native language but who had Japanese parents who back-translated the 13 translated items.
  The questionnaire has the following sections: (a) comprehensibility (five items), (b) manageability (four items), and (c) meaningfulness (four items). Each item was scored on a 5-point scale from "almost never" (1) to "almost always" (5). The total score and sub-scores for comprehensibility, manageability, and meaningfulness were calculated.
- Illness cognition: A 34-item illness cognition questionnaire for which reliability and validity had been demonstrated was used.[4] The original questionnaire has 55 items, and the present 34 were chosen according to factor analysis – principal factor method, promax rotation – with a factor loading of 0.4 as the cut-off. Internal consistency was evaluated with Cronbach's α, and the coefficient of correlation was calculated by test–retest reliability. The questionnaire contained the following sections: (a) hardships resulting from restrictions and limitations of illness (10 items), (b) positive acceptance of one's illness (11 items), (c) the desire to be understood by others (five items), (d) anxieties about the state of the disease and the possibility of death (three items), (e) not wanting people to know of one's disease (three items), and (f) not wanting to take a burden on one's body (two items). Each item was answered on a 5-point scale. Only adolescents with congenital cardiac disease were asked to complete this questionnaire.

Questionnaires were mailed to the adolescents with congenital cardiac disease identified by branch offices of a patient self-help group. Participants completed the forms at home, sealed them, and then sent them back to the researcher. The questionnaires that were sent to healthy adolescents were either mailed back by the participants or collected in a classroom box, depending on the instructions of the school principal.

Data analysis

We investigated the relationship between the sense of coherence, basic and disease-related attributes, and illness cognition in healthy adolescents and those with congenital cardiac disease. Statistical analysis comprised Mann–Whitney *U* tests or Kruskal–Wallis tests, with Bonferroni's correction

https://doi.org/10.1017/S1047951110000685 Published online by Cambridge University Press

for multiple comparisons. $p < 0.05$ was taken to indicate statistical significance. SPSS 16.0J for Windows was used for statistical interpretation. The following points were investigated:

- The influence of background factors on the sense of coherence in adolescents with congenital cardiac disease.
- The difference in the sense of coherence between healthy adolescents and adolescents with congenital cardiac disease.
- The influence of illness cognition in the sense of coherence in adolescents with congenital cardiac disease.

Ethical considerations

A letter requesting participation in the investigation was attached to the questionnaire. This was addressed to the legal guardians too, because the participants were 18 years old or younger.

The letter explained the purpose and methods of the investigation, the investigation contents, that participants could participate of their own free will and had the right to withdraw at any stage of the investigation, anonymity of responses, that data would be used only for the study purpose, that contents identifying an individual would not be published, and that personal data would be destroyed after the end of the study.

Return of the questionnaire was considered to indicate consent to participate. This study was approved by the medical ethics committee of the Medical Department, Osaka University, Japan.

Results

Participant background

A total of 193 adolescents with congenital cardiac disease participated, response rate was 36.1%, of which 21 forms with incomplete data were excluded. Therefore, data from 172 participants were analysed. The average age was 14.7 plus or minus 1.7 years.

A total of 295 healthy adolescents participated, response rate was 73.6%, and all responses were analysed. The average age was 14.7 plus or minus 1.8 years. Tables 1 and 2 show participant background.

Internal consistency among the sense of coherence

Score consistency was evaluated using Cronbach's α. In the congenital cardiac disease group, Cronbach's α was as follows: total, 0.85; comprehensibility, 0.74; manageability, 0.70; and meaningfulness, 0.70. In the healthy group, Cronbach's α was as follows: total, 0.80; comprehensibility, 0.80; manageability, 0.61; and meaningfulness, 0.68.

Table 1. Characteristics of participants with congenital cardiac disease (n = 172).

Participant characteristic	n
School	
Junior high school	89
High school	83
Gender	
Male	86
Female	86
School and gender	
Junior high school boy	44
High school boy	42
Junior high school girl	45
High school girl	41
Disease	
Tetralogy of Fallot	24
Transposition of the great vessels	20
Ventricular septal defect	17
Ivemark syndrome	16
Single ventricle	13
Others	82
Cyanosis	
Yes	112
No	48
No answer	12
Co-morbidities	
Yes	21
No	141
No answer	10
Medication use	
Yes	86
No	85
No answer	1
Number of hospitalisations	
0–5	87
6–10	34
>11	48
No answer	3
Number of operations	
0–2	101
>3	68
No answer	3
Classification on the school life management guidance list	
Severeness	25
Medium	42
No answer	38
Ability to take part in physical education	
None	56
Some	80
All	36

Influence of background factors on the sense of coherence in adolescents with congenital cardiac disease

With regard to basic attributes – age, school year, and sex – junior high school students scored higher than high school students for total sense of coherence, manageability, and meaningfulness. Boys scored higher than girls for total sense of coherence, comprehensibility, and manageability, and junior high school boys scored higher than high school girls for all sections.

https://doi.org/10.1017/S1047951110000685 Published online by Cambridge University Press

Table 2. Characteristics of healthy participants (n = 295).

Participant characteristic	n
School	
Junior high school	141
High school	153
No answer	1
Gender	
Male	44
Female	246
No answer	5
School and gender	
Junior high school boy	23
High school boy	21
Junior high school girl	117
High school girl	129
No answer	5

With regard to disease-related attributes, those with no co-morbidities scored higher for manageability. Those who were hospitalised six to ten times scored higher than those who were hospitalised zero to five times for total sense of coherence, comprehensibility, and manageability (Table 3).

Differences in the sense of coherence among healthy adolescents and those with congenital cardiac disease

When the congenital cardiac disease group and healthy group were compared, the congenital cardiac disease group scored higher for total sense of coherence, comprehensibility, and manageability. This was true for all students, junior high school students, high school students, boys, girls, and junior high school boys. Furthermore, with boys and junior high school boys, the congenital cardiac disease group scored higher for meaningfulness. With junior high school girls, the congenital cardiac disease group scored higher for comprehensibility and manageability. For high school boys, no significant differences were apparent (Table 4).

Relationship between illness cognition scores and sense of coherence scores in adolescents with congenital cardiac disease

Participants with congenital cardiac disease were divided into two groups for illness cognition above and below the average, respectively; the former of which is called high-score group, and the latter is called low-score group. The sense of coherence score was compared in these two groups.

Illness cognition scores were significantly related to sense of coherence scores as follows: low scores for "hardships resulting from restrictions and limitations of illness" were significantly related to higher scores in all sense of coherence elements; lower scores for "the desire to be understood by others" were associated with significantly higher scores for "manageability"; and low scores for "anxieties about the state of the disease and the possibility of death" and "not wanting people to know of one's disease" were related to significantly higher scores for total sense of coherence, comprehensibility, and manageability (Table 5).

Discussion

Influence of background factors on the sense of coherence in adolescents with congenital cardiac disease

For several coherence elements, boys scored higher than girls, and junior high school students scored higher than high school students.

Okamoto noted that decision-making in adolescence is important with regard to choice of occupation, marrying, and becoming a parent.[8] On entering high school, students are confronted with many decisions and this process can be difficult. Adolescents with congenital cardiac disease must make choices that take into consideration their physical ability both now and in the future. A low total sense of coherence score may be exhibited by those adolescents who feel their future is compromised because of their cardiac defect.

When examining sex differences, the sum total of sense of coherence, comprehensibility, and manageability scores for boys was higher than for girls. Britta and Monica[9] found that sense-of-coherence scores for 14- to 15-year-old girls were lower than for boys. Secondary sex characteristics develop much sooner in girls than in boys. Women with congenital cardiac disease experience an underlying sense of being, "at war" with or living against their bodies.[10] Body image issues may be exacerbated in adolescent girls with congenital cardiac disease because of scars as a result of multiple procedures. These stresses may reduce the sense of coherence in adolescent girls. Body image may not be an issue for adolescent boys. They may be more optimistic than girls and therefore score higher on sense-of-coherence questionnaires.

Co-morbidities and the number of hospitalisations had a significant influence on the sense-of-coherence scores. Co-morbidities were associated with a lower score for total sense of coherence and manageability. This may be because the life restrictions by these co-morbidities interfered with the ability to deal with stress. However, manageability scores were higher for those with six to ten hospitalisations compared with those with zero to five, suggesting that moderate stress promoted manageability.

https://doi.org/10.1017/S1047951110000685 Published online by Cambridge University Press

Table 3. Influence of background factors on sense of coherence in adolescents with congenital cardiac disease.

		Sense of coherence (total)		Comprehensibility		Manageability		Meaningfulness	
	n	Mean	SD	Mean	SD	Mean	SD	Mean	SD
School									
Junior high school	92	46.98	6.84**	17.41	3.21	14.74	2.88**	14.83	2.56**
High school	84	42.94	9.07**	16.48	4.09	13.11	3.51**	13.35	3.21**
Gender									
Male	86	46.57	7.97**	17.70	3.39*	14.56	3.15**	14.31	2.90
Female	86	43.49	8.22**	16.23	3.83*	13.35	3.35**	13.91	3.06
School and gender									
Junior high school boy	44	48.59	6.19***	18.11	2.86*	15.45	2.66***	15.02	2.56*
High school boy	42	44.45	9.09	17.26	3.84	13.62	3.36	13.57	3.07
Junior high school girl	45	45.40	7.14	16.73	3.41	14.04	2.95	14.64	2.58
High school girl	41	41.39	8.89***	15.68	4.22*	12.59	3.62***	13.12	3.36*
Cyanosis									
No	48	45.04	9.34	16.71	4.16	13.79	3.84	14.54	3.65
Yes	112	45.02	7.81	17.00	3.53	14.04	3.00	13.99	2.74
Co-morbidities									
Yes	21	41.57	10.29	15.67	4.80	12.00	3.63**	13.90	3.62
No	141	45.60	7.79	17.13	3.50	14.28	3.10**	14.19	2.94
Medication use									
Yes	86	45.10	8.34	17.12	3.37	14.23	3.13	13.75	3.06
No	85	45.00	8.19	16.84	3.99	13.68	3.46	14.48	2.88
Number of hospitalisations									
0–5	87	43.59	8.19**	16.18	4.89***	13.37	3.30*	14.03	3.05
6–10	34	48.94	6.10**	18.93	3.40***	15.35	2.59*	14.67	3.14
>11	48	44.77	8.79	16.92	3.76	13.94	3.48	13.92	2.80
Number of operations									
0–2	101	44.87	8.16	16.82	3.60	13.84	3.40	14.21	3.05
>3	68	44.91	8.37	16.97	3.76	13.97	3.12	13.97	2.94
Classification on the school life management guidance list									
A × B × C (severeness)	25	44.32	9.02	16.81	3.49	13.80	3.65	13.72	2.97
D (medium)	42	45.33	6.50	16.99	3.04	13.93	2.79	14.42	2.95
E × E + Prohibition (slight)	67	44.97	9.62	17.04	4.02	13.84	3.69	14.09	3.48
Ability to take part in physical education									
None	56	45.39	8.61	17.14	3.74	14.07	3.33	14.19	3.03
Some	80	45.41	7.12	17.21	3.17	14.12	2.83	14.08	2.83
All	36	43.61	9.85	16.14	4.52	13.39	4.14	14.08	3.29

Mann–Whitney *U* test, Kruskal–Wallis test, revision by Bonferroni's inequality in multiple comparison. *$p < 0.05$, **$p < 0.01$, ***$p < 0.001$

Table 4. Sense of coherence in adolescents with and without congenital cardiac disease.

		Sense of coherence (total)		Comprehensibility		Manageability		Meaningfulness	
	n	Mean	SD	Mean	SD	Mean	SD	Mean	SD
All students									
Congenital cardiac disease	172	45.03	8.22***	16.96	3.68***	13.95	3.29***	14.11	2.98
Healthy	295	41.22	7.44***	15.00	3.33***	12.13	3.02***	14.09	2.91
Junior high school students									
Congenital cardiac disease	89	46.98	6.84***	17.41	3.21***	14.74	2.88***	14.83	2.56
Healthy	141	42.62	8.33***	15.42	3.62***	12.59	3.38***	14.61	3.09
High school students									
Congenital cardiac disease	83	42.94	9.07**	16.48	4.09***	13.11	3.51**	13.35	3.21
Healthy	153	39.93	6.30**	14.60	3.01***	11.72	2.60**	13.61	2.67
Male									
Congenital cardiac disease	86	46.57	7.97***	17.70	3.39**	14.56	3.15**	14.31	2.90*
Healthy	44	41.89	6.41***	15.82	2.79**	12.93	2.94**	13.14	2.84*
Female									
Congenital cardiac disease	86	43.49	8.22**	16.23	3.83**	13.35	3.35**	13.91	3.06
Healthy	246	41.11	7.68**	14.85	3.43**	12.01	3.05**	14.25	2.92
Junior high school boy									
Congenital cardiac disease	44	48.59	6.19***	18.11	2.86**	15.45	2.66**	15.02	2.56**
Healthy	23	41.52	7.17***	15.57	3.12**	13.35	3.37**	12.61	3.17**
High school boy									
Congenital cardiac disease	42	44.45	9.09	17.26	3.84	13.62	3.36	13.57	3.07
Healthy	21	42.29	5.61	16.10	2.41	12.48	2.38	13.71	2.37
Junior high school girl									
Congenital cardiac disease	45	45.40	7.14	16.73	3.41*	14.04	2.95*	14.64	2.58
Healthy	117	42.85	8.58	15.40	3.74*	12.46	3.39*	14.99	2.94
High school girl									
Congenital cardiac disease	41	41.39	8.89	15.68	4.22*	12.59	3.62	13.12	3.36
Healthy	129	39.53	6.39	14.34	3.05*	11.60	2.65	13.59	2.74

Mann–Whitney U test. *$p < 0.05$, **$p < 0.01$, ***$p < 0.001$

None of the other background factors were shown to influence the sense of coherence in this study. Hence, disease severity does not seem to influence the development of the sense of coherence. As congenital cardiac disease is present from birth, patients tend to develop a sense of normalcy in coexisting with a disease in the long term. For example, patients make statements such as "life with the disease is just my life", "Generally, I am the same as other people", "The disease is one's characteristic", and "I am normal".[11–13]

In addition, disease severity is determined objectively and differs from the subjective perception of health. A previous study showed that recognition of health and the burden of symptoms are not related to the disease state as evaluated by a doctor. Instead, these aspects seem to be strongly related to the degree to which the disease interferes with social relationships.[14] Therefore, the sense of coherence is determined from feelings of restrictions and limitations from illness rather than from disease severity. Adolescents with congenital cardiac disease may think that they have mild disease compared with others.[4] This may prevent them from taking the disease seriously. It may be a characteristic of congenital diseases that affirmative psychological ability is not affected by disease severity.

Differences in the sense of coherence among healthy adolescents and adolescents with congenital cardiac disease

This study showed that the sense of coherence was higher in the congenital cardiac disease group than in the healthy group. Adolescents with chronic illness experience ongoing stress in their daily lives. In particular, they feel stresses related to physical limitations by the disease and medical treatment.[15] It seems that the sense of coherence is reinforced through successful processing of these stresses. These findings are similar to those from studies of resilience; students with congenital cardiac disease have greater resilience than healthy students.[16]

Congenital cardiac disease patients often require repeated hospitalisations and multiple operations. Sense of coherence has been conceptualised as the ability to tackle stress in a positive manner so that stressors promote personal growth. It is influenced by human experience, in other words by interacting with the environment, and it is learned and formed. It therefore seems that experiencing illness as a part of life can positively influence personal growth. However, it means that they must be able to make sense of their world.

https://doi.org/10.1017/S1047951110000685 Published online by Cambridge University Press

Table 5. Difference in the sense of coherence score according to illness cognition score.

	n	Sense of coherence (total)		Comprehensibility		Manageability		Meaningfulness	
		Mean	SD	Mean	SD	Mean	SD	Mean	SD
Hardships resulting from restrictions and limitations of illness									
Low-score group	82	47.16	8.11**	17.71	3.96*	14.83	3.25***	14.62	2.90*
High-score group	90	43.09	7.88**	16.28	3.27*	13.16	3.14***	13.65	2.99*
Positive acceptance of one's illness									
Low-score group	72	44.96	7.81	17.22	3.52	14.03	3.12	13.72	3.26
High-score group	100	45.08	8.55	16.78	3.79	13.90	3.43	14.40	2.73
The desire to be understood by others									
Low-score group	87	45.64	8.58	17.30	3.88	14.38	3.47*	13.97	3.25
High-score group	85	44.40	7.84	16.62	3.44	13.52	3.06*	14.26	2.68
Anxieties about the state of the disease and possibility of death									
Low-score group	92	46.56	8.10**	17.69	3.88**	14.60	3.38**	14.27	2.94
High-score group	82	43.31	8.06**	16.15	3.27**	13.22	3.06**	13.94	3.03
Not wanting people to know of one's disease									
Low-score group	91	46.31	8.69*	17.51	3.80*	14.43	3.62**	14.37	3.01
High-score group	81	43.59	7.46*	16.35	3.45*	13.42	2.81**	13.83	2.93
Not wanting to take a burden on one's body									
Low-score group	84	45.94	8.04	17.15	3.67	14.17	3.29	14.63	3.08*
High-score group	88	44.16	8.34	16.79	3.70	13.75	3.30	13.62	2.81*

Mann–Whitney U test. *$p < 0.05$, **$p < 0.01$, ***$p < 0.001$

Relationship between illness cognition and sense of coherence in adolescents with congenital cardiac disease

Those who scored high for "hardships resulting from restrictions and limitations of illness" scored poorly for all sense-of-coherence elements. Moreover, those who scored high for "anxieties about the state of the disease and the possibility of death" scored poorly for total sense of coherence, comprehensibility, and manageability.

In adolescence, school and peers are the main focus of life. Restrictions and limitations posed because of illness decrease the feeling of a meaningful life. Congenital cardiac disease is present from birth. Parents are the recipients of the explanation of their child's illness. If this information is not passed on to the adolescent at the appropriate stage of development, the adolescent may experience anxiety about the state of their condition. They cannot then make sense of their world and this will reduce the comprehensibility and manageability elements.

Those who scored high for "the desire to be understood by others" scored poorly for manageability, and those who scored high for "not wanting people to know of one's disease" scored poorly for total sense of coherence, comprehensibility, and manageability.

Ishikawa[17] has shown that there is a relationship between self-disclosure and social support. Those who scored low for "not wanting people to know of one's disease" can freely discuss their illness with friends, and this is likely to result in greater social support and the sense of having enough resources, including friendships, to deal with life. Conversely, those scoring high for "the desire to be understood by others" are unlikely to obtain enough social support. In this way, it seems that lack of support from others decreases manageability.

Methods of supporting sense of coherence in adolescents with congenital cardiac disease

Those who scored low for "hardships resulting from restrictions and limitations for illness", "anxieties about the condition of disease and the death", or "not wanting people to know of one's disease" tended to have higher sense-of-coherence scores. This indicates that supporting the development of sense of coherence may promote affirmative illness cognition. A study investigating illness cognition and resilience in the same group of participants[18] showed that the sense of "I am" (internal strength) was high in those who scored poorly for "hardships resulting from restrictions and limitations for illness", "anxieties about the condition of disease and the death", and "not wanting people to know of one's disease". Hence, supporting the development

https://doi.org/10.1017/S1047951110000685 Published online by Cambridge University Press

of the sense of coherence may promote this personal internal strength.

Sense of coherence in adolescents with congenital cardiac disease was higher than that in healthy adolescents, reflecting the fact that the sense of coherence is strengthened by repeated successful experiences in handling stress. This may be similar to the situation in patients with type 1 diabetes mellitus who must confront various problems from later in childhood and are thought to deal well with psychological problems in adolescence.[19] This indicates the importance of dealing with stressors in the illness experience. Therefore, efforts to remove stressors by overprotection are not necessary. Instead, we should keep an eye on children who are attempting to deal with stressors by themselves and offer help if required.

Children and adolescents with congenital cardiac disease have poorly developed self-efficacy and self-concept.[10,20] The present finding of a strong sense of coherence seems to contradict this, but it can be understood as follows. Self-efficacy and self-concept consist of trust in oneself. Although the sense of coherence relies on trust in the environment, including the social support network, family, and peer group,[17] it is a concept connected with "interaction with and dependence on the environment". In adolescence, which is the transition from childhood to adulthood, factors important in reinforcing the sense of coherence are school life, family life, and social support.[21]

For young people with congenital cardiac disease, support and understanding from parents, friends, and teachers are crucial.[22] The amount of required social support is related to the extent of self-disclosure.[17] It is therefore important that adolescents with congenital cardiac disease feel supported and cared for by their parents, family, friends, and teachers.

Limitations

Participants in this study were members of a patient self-help group; therefore, awareness of the disease was high. Research into those who are not members of such groups will be necessary in future. In addition, this study had no comparison group for illness cognition. Therefore, it is hard to determine whether illness cognition was adequately assessed with regard to the specific characteristics of adolescents with congenital cardiac disease. Inclusion of a group with another chronic disease will be necessary in future research.

Conclusion

- Sense of coherence was higher in boys than girls and in junior high school students than high school students.
- Sense of coherence was higher in students with congenital cardiac disease than in healthy students.
- With regard to illness cognition, low scores for "hardships resulting from restrictions and limitations of illness", "the desire to be understood by others", "anxieties about the condition of disease and the death", and "not wanting people to know of one's disease" were related to a high sense of coherence.

This study expanded on and revised part of my doctoral dissertation submitted to the Course of Health Science, Graduate School of Medicine, Osaka University. This dissertation was presented at the 27th Academic Conference of the Japan Academy of Nursing Science in 2007.

References

1. Niwa K. Adult congenital heart disease. Jpn J Pediatr Med 2001; 33: 616–621.
2. Niwa K. Sentensei Shinshikkan no Katano Tameno Ninshin, Syussan Guidebook. Chuohokisyuppan, Tokyo, 2006.
3. Antonovsky A. Unraveling the Mystery of Health; How People Manage Stress and Stay Well. Jossey-Bass Publishers, San Francisco, 1987.
4. Nio K. A structure of illness cognition of junior high school and high school students with congenital heart disease. J Jpn Soc Child Health Nurs 2008a; 17: 1–8.
5. Sakano J, Togari T, Yamazaki Y, et al. Jidouyou SOC scale 13 koumokuban (CSOC13jp) no kaihatsu. Journal of Japanese Health Education and Promotion 2004; 12 (Suppl): 182–183.
6. Tosheim T, Aaroe LE, Wold B. Aense oh coherence and school-related stress as predictors of subjective health complaints in early adolescence:interactive, indirect or direct relationships? Soc Sci Med 2001; 53: 603–614.
7. Hyashi H, Kobayashi M, Yamazaki Y. Zen-shishunkiyou kennkouhojinouryojku SOC scale no kaihatsu to ouyou. J Jpn Health Educ Promot 2003; 11 (Suppl): 106–107.
8. Okamoto Y. Seinenki ni okeru ishikettei. In: Ochiai Y and Kusumi T (eds). Koza Syougaihattatushinrigaku No 4 Jikohenotoinaoshi-seinenki. Kanekosyobou, Tokyo, 1995.
9. Britta M, Monica L. Health behaviour and sense of coherence among pupils aged 14–15. Scand J Caring Sci 2006; 20: 339–346.
10. Gantt LT. As normal a life as possible; mothers and their daughters with congenital heart disease. Health Care Women Internat 2002; 23: 481–491.
11. Nio K, Fujiwara C. Illness perception of adolescents with congenital heart disease. J Child Health 2003; 62: 544–551.
12. Tong EM, Sparacino PSA, Messias DKH, et al. Growing up with congenital heart disease; the dilemmas of adolescent and young adults. Cardiol Young 1998; 8: 303–309.
13. Takahashi K. Thoughts of children in adolescence who with congenital heart disease. Nurs J Osaka Univ 2002; 8: 12–19.
14. Kendal L, Lewin RJP, Parsons JM, et al. Factors associated with self-perceived state of health in adolescents with congenital cardiac disease attending paediatric cardiologic clinics. Cardiol Young 2001; 11: 431–438.
15. Nakamura N, Kanematsu Y, Takeda J, et al. Stress experienced by children with chronic disease. J Child Health 1996; 55: 75–81.

16. Nio K. Resilience of junior and senior high school students with congenital heart disease: differences in resilience due to attributive factors. J Child Health 2008b; 67: 826–833.
17. Ishikawa M. Relationship between self-disclosure of adolescent with congenital heart disease, self-esteem and social support. J Jpn Soc Child Health Nurs 2008; 17: 1–8.
18. Nio K. Resilience of junior and senior high school students with congenital heart disease; differences in resilience due to illness cognition. J Child Health 2008b; 67: 834–839.
19. Yokota Y, Matsuura N. Shisyunki mansei shikkanji heno taiou – tounyoubyou. Pediatrics of Japan 2003; 44: 1504–1509.
20. Salzer-Muhar U, Herle M, Floquet P, et al. Self-concept in male and female adolescents with congenital heart disease. Clin Pediatr 2002; 41: 17–21.
21. Kamiduka N, Kobayashi M, Yamazaki Y, et al. Chugakusei no stress taishonouryoku SOC to sonoyouin ni kansuru kentou. J Jpn Soc Health Educ Promot 2005; 13: 222–223.
22. Kendall L, Sloper P, Lewin RJP, et al. The views of young people with congenital cardiac disease on designing the services for their treatment. Cardiol Young 2003; 13: 3–6.

https://doi.org/10.1017/S1047951110000685 Published online by Cambridge University Press