READINESS OF CHILDREN WITH CONGENITAL HEART DISEASE TO ADAPT BODILY SENSATIONS TO THEIR LIVING CONDITIONS

Masako AOKI*   Chihiro HINUMA*

Abstract

Aim: The aim of this study was to explore the readiness of children with congenital heart disease to adapt their bodily sensations to their living conditions.

Methods: The participants were 8 children with congenital heart disease, aged 10–17 years, who were individually interviewed. Taped and transcribed interview data were analyzed using a grounded theory approach.

Results: Children with congenital heart disease who were learning to control the awareness of their bodily sensations and condition exhibited a readiness to adapt based on individual needs. The readiness to adapt consisted of 4 categories: (i) understanding their bodily signals; (ii) disclosure of information about their body; (iii) exploring relationships with friends; and (iv) conscious of their own potential. To develop readiness, children must understand their bodily signals on their own, disclose information when necessary, and learn to apply that information.

Conclusions: Encouraging the development of readiness helps children with congenital heart disease adjust to their bodily condition. These points will provide direction for concrete initial care and long-term support plans during the growth and development of such children, enabling them to expand their range of physical activities and be independent in school life and the environment.

Key words: child, bodily sensation, adaptation, congenital heart defects
INTRODUCTION

The long-term survival of children with congenital heart disease (CHD) is increasing, allowing these children to enjoy social participation; this has led to the need to accelerate initiatives focusing on the quality of life so that these children can cope with various issues that arise as they grow and develop (Nio, 2010; Ando & Hasegawa, 2005). Changes in the living environment during the growth of children with CHD can cause fatigue and distress, and factors such as limitations of movement and decreased cardiac function may have unexpected results. Moreover, children with CHD are forced to develop techniques for caring for their bodily condition as their range of activities expands or as their symptoms change, even if their medical condition does not require vigilant management. As children with CHD grow older, they must continue to cope with changes in their condition, even after completing treatment.

Children expand their range of activities and become more interested in building friendships upon reaching school age and during early adolescence (Nio, 2010). Although the physical condition of children with CHD may be more stable during these stages, they are forced to adjust to their changing physical condition on their own when they are away from their family. Previous studies have shown that adolescents with CHD have a low quality of life and low self-esteem (Salzer et al., 2002); this low self-esteem has been attributed to their reduced physical abilities (Cohen, Mansoor, Langut, & Lorber, 2007). However, studies in Japan have shown that children with CHD become more aware of their bodies and the surrounding environment, and develop the skills to adjust to their bodily condition (Aoki, 2009). It is important for children to develop self-care techniques and independence while being treated for CHD (Nio, 2010; Tong et al, 1998); these are essential skills for a child’s wellbeing after treatment. Therefore, this study focused on the inherent bodily control awareness of children with CHD while they adjusted to their physical condition. The present study aimed to clarify the readiness of children with CHD to adapt bodily sensations to their living conditions.

METHODS

In the present study, a qualitative design based on the grounded theory approach (Strauss & Corbin, 1998) was used for data collection and analysis. Qualitative methods can be used to obtain intricate details regarding feelings, thought processes, and emotions that are difficult to extract or learn through more conventional research methods (Strauss & Corbin, 1998). More importantly, the grounded theory approach uses symbolic interactionism as a theoretical background. Children grow and develop through interactions with their environments; to explore this, children’s complex experiences must be understood from their perspective. Thus, the grounded theory approach was used to provide a meaningful guide of children’s bodily sensations. Children’s bodily sensations can be understood as a phenomenon derived from social interaction, which can be interpreted, treated, and modified.

Participants

The participants were children with CHD, aged 10–17 years, who could express their personal experiences. No criteria regarding disease qualifications or lifestyle limitations were defined. A self-help group for children with heart disease and their families was asked to recommend candidates. Candidates were sent a written request for participation by post, and were requested to reply only if they wished to participate in the study. Responses were received from 9 individuals. One participant was excluded midway through the study after the participant’s desire to drop out became apparent during the interviews; thus, 8 participants completed the interviews.

Data collection

Data were collected using semi-structured interviews in 2008. The interview guides comprised the following questions: (i) Is your physical condition good? How do you consider your physical condition? (ii) Have you ever been troubled or worried about your physical condition in school life? (iii) Is there anything about your body that you feel is strange or unusual? (iv) Please tell me what you like about yourself or something about yourself that you are proud of.

Interview dates and locations were determined based on the participants’ requests, and interviews were held in locations in which the participants’ privacy could be protected. Participants were asked questions based on the interview guide, and they were asked to freely express their thoughts regarding their bodies, concerns for their bodies, detection of changes, and responses to changes in physical condition. The
interviews were recorded using a recorder after permission was received from the participants. The recordings were transcribed verbatim and used as data.

Data analysis
Data were analyzed based on the ground theory approach (Strauss & Corbin, 1998). First, the data from the participants were read to understand the context of the responses. Second, content that involved thoughts or episodes concerning their bodies, perception of changes, and method of responding was segmented into single sentences or blocks of text. Properties and dimensions were extracted from the segmented data, which were then given a label to indicate the meaning. Next, the properties and dimensions were evaluated and the labels were categorized into batches based on semantic content. The relationships between the categories and subcategories were examined, and a storyline was created. This type of analysis was carried out for each participant’s interview. The categories and data were compared between each participant and the next for continuous refinement of the categories. Qualitative nursing science researchers supervised the proceedings during the analysis, and reviewed and corrected the analyses as necessary.

Ethical considerations
The ethics committee of the International University of Health and Welfare and the CHD self-help group approved this study. The participants and their parents or guardians were provided with the following statements in writing: the purpose and methods of the study, voluntary nature of participation, guarantee of the right to discontinue the interviews, elimination of liability, protection of privacy, and method of presenting the results. The participants and their parents or guardians consented in writing to participate in the study. Continuous and meticulous efforts were made to ensure that our actions did not hinder the participants’ academic progress or daily life. During the interview, the expression and state of the children were carefully monitored. After the interview, we took care for maintain the psychological condition of stability of children.

RESULTS

Participants’ profiles
The participants were 8 children aged 10–17 years. Three children were in elementary school, 3 in junior high school, and 2 in high school (Table 1).

Readiness of children with CHD to adapt their bodily sensations
The results of the analyses showed that the participants’ readiness to exercise their ability to adapt consisted of 4 categories: (i) understanding their bodily signals, (ii) disclosure of information about their body, (iii) exploring relationships with friends, and (iv) conscious of their own potential (Table 2). In this study, friends included schoolmates, and peers included children with CHD.

According to their views on their physical condition and illness, the participants exhibited “understanding their bodily signals”. In addition, participants were provided information about illness by their parents. When participants displayed “understanding signals from the body,” they could maintain their own indices of bodily sensations to correctly understand their bodies in their own way. When participants wished to perform an action or when they began to feel bad, they would “disclosure of information about their body” for a certain purpose, in which they provided explanations to their friends. For “exploring relationships with friends,” the participants

<table>
<thead>
<tr>
<th>Subject</th>
<th>Age (years)</th>
<th>Sex</th>
<th>Diagnosis</th>
<th>Health condition</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>13</td>
<td>Male</td>
<td>Single ventricle, single atrium</td>
<td>Good; cardiac pacemaker insertion</td>
</tr>
<tr>
<td>B</td>
<td>11</td>
<td>Male</td>
<td>Right-sided single ventricle</td>
<td>Good</td>
</tr>
<tr>
<td>C</td>
<td>10</td>
<td>Male</td>
<td>Undetermined</td>
<td>Good</td>
</tr>
<tr>
<td>D</td>
<td>13</td>
<td>Female</td>
<td>Ventricular septal defect, other</td>
<td>Good</td>
</tr>
<tr>
<td>E</td>
<td>17</td>
<td>Female</td>
<td>Right-sided single ventricle</td>
<td>Good</td>
</tr>
<tr>
<td>F</td>
<td>16</td>
<td>Female</td>
<td>Tetralogy of Fallot</td>
<td>Good; check-up once every 6 months</td>
</tr>
<tr>
<td>G</td>
<td>14</td>
<td>Female</td>
<td>Complete transposition of the great arteries</td>
<td>Good; using oxygen</td>
</tr>
<tr>
<td>H</td>
<td>10</td>
<td>Female</td>
<td>Complete transposition of the great arteries</td>
<td>Hospitalized</td>
</tr>
</tbody>
</table>
indicated that they exchanged information, which helped their friends to understand them; thus, belief in their similarities with their friends was weakened and replaced with belief in their own individuality. In the present study, the children overcame differences between themselves and their friends and began to acknowledge their own unique personalities. They began “conscious of their own potential,” which they felt within themselves due to their physical condition. Using their “understanding their bodily signals” as a foundation for correctly understanding and applying information regarding their physical condition helped them to change and adjust to their own bodily sensations and the environment, including friends and circumstances.

Conversely, children who were weak at “understanding their bodily signals” and could not appropriately understand the signals felt that they were being judged by friends, and thus feared their differences and kept the information to themselves. In turn, they had little respect for their bodies, and underestimated and misunderstood themselves. Consequently, some children tended to refuse to “disclosure of information about their body” to others. “Exploring relationships with friends” then became difficult for these children, and rather than prevent misunderstandings, they chose to escape reality. As a result, even when they became more interested in their bodies, they lacked mobility, did not have positive feelings, and could not become motivated to adjust on their own.

---

**Table 2. Readiness of children with congenital heart disease to adapt to their bodily sensations**

<table>
<thead>
<tr>
<th>Category</th>
<th>Sub-category</th>
</tr>
</thead>
</table>
| 1 Understanding their bodily signals | Understood hemodynamics  
Signals of changes presently occurring  
Signals that predict future changes  
Unnoticed bodily signals  
| 2 Disclosure of information about their body | Disclosure of illness information  
Disclose information to expand their personal freedom  
Disclose information to receive support  
Keeping the bodily information secret  
| 3 Exploring relationships with friends | Want to be the same  
Be accepted understanding about characteristics  
Receive the friend's support  
Individuality is acceptable  
Get the wrong impression  
| 4 Conscious of their own potential | Awareness of own bodily excellence  
Conscious of the ability being able to perform normally  
Awareness of the positive effects of illness  
Conscious of their bodily limitations  |

Sub-categories that may cause a negative sequence of events

**Understanding their bodily signals**

Participants “understood hemodynamics” in their own way and sensed “signals of changes presently occurring” and “signals that predict future changes” in their physical condition. Changes included those that were and were not externally visible. Visible changes included changes in skin or lip color, which “turned purple.” Invisible changes included whole-body sensations as perceived by the child, such as fatigue or difficulty breathing. Once the participants had accumulated information regarding personal sensation experiences, they were able to predict changes in their bodies with a unique perception of “signals that predict future changes,” such as a slight increase in heartbeat.

I get tired, tired. I feel like I have lost stamina or something. In the style of Ultraman (a Japanese superhero), it’s like the warning light is blinking, pi-kkon, pi-kkon. My heart starts beating hard, like Ultraman’s color timer. For me, this is a signal that I should rest a bit. (C)

Additionally, when the participants who had not experienced serious health problems were included in enjoyable activities with friends, they experienced “unnoticed bodily signals” or sensations in their own bodies that they may not have recognized; for example, (H) said, “When I’m doing something fun, I can’t stop (what I’m doing). My mom stops...
me. I don’t realize by myself that I’ve started feeling bad. I can’t stop, I keep doing what I’m doing.”

Disclosure of information about their body
Participants learned about their bodies and the states of their heart disease through “disclosure of illness information” from their parents. Based on a unique understanding of their physical condition, participants used their own words to “disclose information to expand personal freedom” and “disclose information to receive support” from their friends in order to prevent physical difficulty. They disclosed information regarding the state of their illness, actions that they could not complete, and reasons they could not participate in specific activities. Information was disclosed to the child by the parents; teachers, school nurses, and principals at school; and classmates, by the child to friends, and by the supervisor to the child’s classmates.

I told my friends on my own. I have a bad heart and can’t do the same things as everyone else. But I want to do the same as everyone else. That’s why I want them to know. So I told them. I started telling them by myself in the upper grades of elementary school. I know myself the best, so I have to be the one to tell them. Because my parents don’t know how I feel. (A)

Regarding their heart disease, some children admitted to “keeping the bodily information secret” from friends. They strategically hid bodily information to prevent receiving preferential treatment and to prevent misunderstandings. However, they felt that they wanted their friends to know at some point.

It’s better that my friends don’t know about my illness. Because my friends will tell me, ‘you have heart disease,’ and they’ll treat me like someone with heart disease.(C) My friends should know. Because if they don’t know, when I’m sitting out in gym class, they’ll ask me, ‘why are you only watching?(D)

Exploring relationships with friends
Responses regarding core friends at school indicated that they sometimes “got the wrong impression,” depending on how the participant conveyed information about heart disease or the friend’s capability for acceptance.

Not everyone understands, so when I come to school late, they think I’ve slept in. I say, ‘No, I was at the doctor’s office.’(E)

As children with CHD are ill, they sense differences in physical strength between themselves and their friends; they cannot participate in the same activities, and their bodies require them to limit their activities. This leads to feelings of alienation and misunderstanding. To blend in with their friends, they “want to be the same” and push their physical limits.

When I’m the only one sitting out during long-distance runs, and everyone is running even though it’s tough…. I feel guilty like I’m cheating or something. I wanted to do sports, but was not able to do. Heart disease is an illness that you cannot see with your eyes, so my friends don’t understand my situation. So I felt I had to do the same thing as them. (E)

Nevertheless, their relationships with friends sometimes exhibited changes. In addition to attempting to assimilate with their friends by learning about their physical limits and gaining understanding from others, insistence on their differences became their unique characteristic, and they realized that their “individuality is acceptable.”

Just running with everyone, despite my illness, I feel okay, because, while running, I am thinking that I am more amazing than all the others. I am amazing because I run at the same pace as all the others, even though I am running with an added weight on my back and they are not. If anything, I am amazing.(A)

The participants were also able to gain understanding from friends as they “receive understanding” about their illness and their personal characteristics and “receive support” when needed. As children with CHD and their friends grow and develop, they consider other people’s circumstances and are better understood by their friends.

When I started high school, my friends started seeing me as a new person. Not just as someone with a disease. My friends started focusing on my human nature and
Conscious of their own potential

As the range of activities expands as children with CHD grow, they begin to feel that their actions do not always produce the expected results. They begin to understand that they “conscious of their bodily limitations” and sometimes become tired of their illness.

I don’t like that every month I have to visit the doctor, or that I sometimes have to leave school early, or that I can’t do because I have a bad heart condition. I can’t participate in gym class and athletic meets days. On those days, I am the only one that has to sit them out, and I feel like I am different from normal friends. I hate being sick. I just want to do a little more, but it’s impossible because my body can’t keep up. (G)

Conversely, the participants did not always only recognize their bodily limitations; they sometimes began to understand their bodies, gained understanding from others, and tested their physical condition and limitations on their own, giving them a sense of the abilities that they acquired, such as “awareness of own bodily excellence” and “conscious of the ability being able to perform normally.”

When I come to understand (my bodily signals), my body becomes more useable. It’s not a machine, but I feel like it becomes more useable. I get the timing for taking a rest, I start to understand sense like that. Anyways, to me, I feel like it’s an amazing power that is at the maximum. (C)

Additionally, the participants would review their current bodily condition and changes, and by seeking the limits of their capabilities despite their illness as well as attempting to predict the future, they learned that their own bodies have potential. Even when their symptoms changed or worsened, they had an idea of how they could respond; furthermore, when they recognized their strengths, they began to sense or hope that living with their condition was acceptable.

It’s like, when I’m tired, I take a rest and then I feel better. If I need to, I can always visit the school nurse. The school nurse knows it… I guess it’s no problem. (G)

Because I can play baseball in spite of illness, I feel that I can do anything like everybody. And maybe I can do anything in the future. (A)

They noticed their own strengths in addition to their physical abilities. They felt that they “aware of the positive effects of illness,” as shown by their expressions of gratitude to others and their illness.

But I learned through my illness. I learned about contents like the importance of life. People often say that objects they buy are valued as treasures. You can never buy friends or family, no matter how much money you spend. So I learned. So I kind of feel like it’s a good experience I am sick. (D)

**DISCUSSION**

The readiness of children with CHD to adapt to their bodily sensations includes positive and negative elements. Based on our results, it is apparent that in order to independently adjust to conditions concerning their bodies, the readiness of the children must be properly developed. Positive bodily sensations will allow children to balance their own assessments and responses to new circumstances in the surrounding environment or physical condition, enabling appropriate adjustments. This state increases their interest in their bodies; moreover, rather than perceiving limitations caused by their condition, they begin to respect their bodies and become open to the idea of expanding their range of activities. This may add to the resilience required for children with CHD to become more independent (Nio, 2008), which is an important skill that should be acquired early in life. Furthermore, “understanding their bodily signals,” was the foundation component of the children’s readiness to adapt. Children must be able to incorporate bodily sensations into their lives and bodies by “understanding their bodily signals.” The understanding of bodily signals will allow these children to develop coping strategies to match bodily condition management for the demands imposed by different situations. In this study, children whose “understanding their bodily signals,” particularly “unnoticed signals,” was weak feared their differences, refused to “Disclosure of information about their body” to anyone else, and stated that this was “information they want to keep secret.” They underestimated
and misunderstood themselves. Therefore, “exploring relationships with friends” was difficult for these children. Additionally, they chose to escape reality rather than preventing misunderstandings. Moreover, these children insisted that they have bodily limitations, lacked free mobility, did not have understanding their own potential, and could not be motivated to adapt on their own. Thus, “understanding their bodily signals” is important for the following reasons.

First, for children to comprehend signals from their bodies, they must correctly understand their illness. Vagueness and uncertainty of physical information prevent progressive understanding of the illness (Nio, 2010; Aoki, 2009). Furthermore, a lack of understanding regarding the illness prevents children from knowing how to accept themselves with their illness and from recognizing their illness (Nio, 2010). Children must be provided information on their condition; however, this does not necessarily have to be detailed medical information. Information should be suited to the child’s developmental stage and powers of comprehension with regard to their experiences and sensations or feelings. When learning self-care skills at a younger age, children are influenced by the values of family members and others who are close to them (Tabata, 2010; Mizuno, 2007). The way family members understand the illness also affects the child’s school life and medical treatment (Mizuno, 2007; Ando & Hasegawa, 2005). Therefore, support systems that promote understanding of the illness by the child’s family members are required.

Second, when children understand their bodily condition and changes on their own, they can set their own guidelines to help them to understand how far they can push themselves, even with the limitations caused by their illness. This also creates opportunities for them to determine when to attempt the next step if they feel that they can shoulder the burden of moving forward. It has been suggested that high school students with CHD must be provided with correct information and chances for self-determination to identify solutions on their own (Tabata, 2010). Therefore, understanding their bodily condition may be an essential skill for independent adjustment to increase the experience of self-determination.

Third, if children can correctly understand signals from their bodies, they will be able to recognize that their limitations are not due to their own shortcomings, but to their illness. This can minimize feelings of self-denial and self-reproach as well as protect their self-esteem. If children respect their bodies, their self-esteem will grow and lead to hope (Aoki, 2009; Nio, 2008), making it easier to disclose information to others and help develop friendships into relationships in which understanding and support are received (Ishikawa & Narama, 2010; Aoki, 2009; Tong et al., 1998). Previous studies have reported that, to a great extent, a reduced perceived capacity and lack of self-esteem can be attributed to reduced physical ability (Cohen et al., 2007; Salzer et al., 2002). However, children can expand the range of activities of which they are actually capable in the process, learn what is within the acceptable range, develop guidelines of what is allowed, and maintain hope and images thereof for the future. They may gradually attempt to adjust to themselves and the environment, thereby helping them adjust to these factors more quickly. This may have an important impact on children expanding their range of life activities without underestimating themselves.

These points suggest the need for support to help children in “understanding their bodily signals” in their own way. This is because adolescents, whose daily lives become more focused around friendships at school when they are away from their parents, convey information to their friends. Understanding their own condition is a critical element for actively responding and preparing in advance for the reactions of friends and current circumstances. Particularly, the more thoroughly children understand their bodily signals and information regarding their bodies, the better they can appropriately respond to misunderstandings by their friends. Understanding their bodily condition will help them explain their current state to others and gain understanding and support from friends (Ishikawa & Narama, 2010; Nio, 2010; Tong et al., 1998); doubtlessly, this is an important skill for their future.

For children with type 1 diabetes mellitus, parents must recognize their children’s symptoms because complications increase when diagnosis is delayed (Xin, Yang, Chen, Tong, & Zhang, 2010). However, children with CHD understand their symptoms of heart disease based on their earliest memories (Nio, 2010; Aoki, 2009). Therefore, children with CHD should recognize the differences between safe activities and abnormal bodily signals. Salzer et al. (2002) found that it is important to identify other activities that may build self-esteem. This study promoted encouraging children to learn skills to help them understand their bodily signals on their
own, and suggested the implementation of concrete support
beginning from the initial stages to long-term support.

Thus, nurses should learn children’s methods of expressing
and perceiving their bodily sensations; they should also use
this knowledge to understand children’s living conditions and
health status so that they can accurately assess their condition
and continuously evaluate the results with the children. The
practical application of these support measures requires
nurses to understand the physical condition of children living
outside the hospital. The field of nursing in Japan, however, is
not equipped with the systems, skills, or authority to closely
monitor children’s lives or to understand and determine their
condition. Therefore, nurses providing care to children with
CHD should be required to collaborate with school nurses or
teachers as well as to incorporate outpatient nursing. These
are policy issues regarding nursing in Japan that must be
considered in order to provide practical long-term support to
such children.

The present study had some limitations and some questions
remained unanswered. This study analyzed data based on
the attributes of participants belonging to a single patient
advocacy group. Therefore, these results have limited
applications and do not achieve theoretical saturation.
Additionally, this study did not take into account the
severity of CHD or the children’s lifestyle limitations.
A continuous comparative review will be conducted that
includes the assessment of characteristics based on the
children’s symptoms and lifestyle limitations and according
to their parents. Conducting practical intervention studies and
investigating support measures are challenges that must be
addressed in future studies.

CONCLUSION

This study found that the readiness of children with CHD to
adapt to their bodily sensations includes (i) understanding
their bodily signals, (ii) disclosure of information about
their body, (iii) exploring relationships with friends, and (iv)
conscious of their own potential. For children to develop
readiness to exercise adjustment abilities, they must
consciously and thoroughly understand their health status
and changes throughout their daily lives. Regardless of
whether these signals from the body are visible, gradually
incorporating children’s unique methods of understanding
bodily signals and applying that information will enable
adjustment according to their whole-body condition and
surrounding environment. This may contribute to the
provision of support for these children to acquire their own
body-control awareness, increase their self-esteem, expand
their range of activities, and increase their independence,
 despite their illness.

ACKNOWLEDGEMENTS

The authors would like to express their sincerest gratitude to
the participating children who provided information regarding
their experiences, as well as to their families. This study was
supported by a Grant-in-Aid for Scientific Research (Grant-
in-Aid for Young Scientists Start-up: 19890204). The abstract
was presented at the 1st International Nursing Research
Conference of the World Academy of Nursing Science.

REFERENCES

no seishinn shinriteki mondai. In: Takao, A., Monma,
K., Nakazawa, M., Nakanishi, T. (Eds). Clinical
Tokyo: Chugai-Igakusha.

Aoki, M. (2009). The creation of a natural sense: The self-
construction of children with congenital heart disease
by body-image. Journal of Japan Academy of Nursing

Quality of life, depressed mood, and self-esteem in
adolescents with heart disease. Psychosomatic Medicine,
69, 313-318.

disease and the related experience in adolescent children
with congenital heart disease. Journal of Japanese

Mizuno, Y. (2007). The change of difficulty and cope that
mothers of infants with congenital heart disease. Journal
of Chiba Academy of Nursing Science, 23, 61-68 (in
Japanese).

students with congenital heart disease: differences in
resilience due to illness cognition. Journal of Child

Nio, K. (2010). Sense of coherence in adolescents with
congenital cardiac disease. Cardiology in the Young, 20,


