



## Psychosocial Factors Influencing Mental Health in Adults With Congenital Heart Disease

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**Background:** Although adult congenital heart disease (ACHD) patients encounter unique challenges related to social adaptation and mental health, only minimal research has been conducted on this functioning in Japanese ACHD patients. The aims of this study were to describe aspects of the psychosocial functioning of ACHD patients and to determine the psychosocial factors influencing their mental health.

**Methods and Results:** Seventy-two ACHD patients (aged 18–39 years) and 86 control participants (aged 18–39 years) completed the 36-item Short Form Health Survey, a measure of mental health, and 4 self-report questionnaires measuring aspects of psychosocial functioning: Independent-Consciousness, Problem-solving, Locus of Control, and Self-esteem. Compared to the control group, ACHD patients had significantly lower scores for Independence, Problem-solving, and Self-esteem; whereas they had higher scores for Dependence on Parents. To examine the psychosocial factors influencing mental health, a structural equation model was used. The psychosocial factor Problem-solving was found to have the most direct influence on mental health. This factor was associated with Independence and Self-esteem.

**Conclusions:** ACHD patients in Japan have psychosocial difficulties, and the psychosocial factors influencing patients' mental health are social problem-solving, independence, and self-esteem. The patients have poorer abilities than the control group in all of these areas and hence, they run the risk of developing poor mental health. (*Circ J* 2013; **77**: 749–755)

**Key Words:** Adult; Congenital heart disease; Mental health; Psychosocial functioning

Recent advances in medical and surgical management have made it possible for many infants with congenital heart disease (CHD) to survive until adulthood. The number of adult CHD (ACHD) patients in Japan who survive beyond the age of 15 has increased to 410,000, at a rate of 9,000 per year.<sup>1</sup> Medical problems related to heart disease, such as residual symptoms and sequelae have been observed in patients who reach adulthood,<sup>2</sup> but there has been a shortage of cardiologists and special facilities dedicated to ACHD patient care.<sup>3,4</sup> In addition, there are psychosocial issues related to mental health in such cases.<sup>5,6</sup>

Currently, most research on the psychosocial aspects of ACHD patients are conducted in Europe and North America using questionnaires and interviews. The results of these studies, however, are inconsistent. Some questionnaire studies found no differences in emotional and social functioning between ACHD patients and the reference group,<sup>7–9</sup> while psychiatric diagnostic interview with adult patients has indicated that one-

to two-thirds of these patients have some psychiatric issues.<sup>10–12</sup> It has been noted that these reported differences in psychosocial adjustment depend on the country in which patients reside and might reflect an aspect of the particular sociocultural environment, such as the health-care system and mental health treatment.<sup>13,14</sup> Therefore, ideally, each country should conduct its own studies of ACHD. In Japan, however, only minimal research has been conducted on psychosocial functioning in ACHD patients.

Moreover, in order to understand patients' psychosocial difficulties, it is necessary to consider the psychosocial mechanisms that influence the relationship between psychosocial factors and mental health.<sup>15,16</sup> Interview studies showed that patients' unique psychosocial functioning is caused by parental overprotection, excessive physical restrictions, and uncertain prognoses. These factors may hinder independence and social skills development, and they could also lead to a lack of self-confidence and of self-control.<sup>10,17,18</sup> On the basis of these

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Table 1. ACHD Subject Characteristics	
	n=72
<b>Age (years)</b>	26.1±5.5 (18–39)
<b>Male</b>	41 (57)
<b>Ethnicity</b>	Japanese
<b>Education level</b>	
>High school education	37 (51)
<b>Employment</b>	
Full time	42 (58)
Part-time	8 (11)
Unemployed	6 (8)
Housewife	5 (7)
Student	11 (15)
<b>Marital status</b>	
Married	13 (18)
<b>NYHA</b>	
I	62 (82)
II	9 (13)
III	1 (1)
<b>Defect complexity</b>	
Simple	13 (18)
Moderate	39 (54)
Great	20 (28)
<b>Cyanotic CHD</b>	35 (49)
Surgical repair	30 (42)
Palliative operation (unrepaired)	5 (7)
<b>Acyanotic CHD</b>	37 (51)
Surgical repair	25 (35)
Observation (no surgery)	12 (17)
<b>Pulmonary hypertension</b>	1 (1)
<b>Medication</b>	
No heart medication	32 (44)
β-blocker	16 (22)
ACEI and/or ARBs	20 (28)
Digoxin	8 (11)
Diuretics	5 (7)
Warfarin	18 (25)

Data given as mean±SD (range) or n (%).

ACEI, angiotensin-converting enzyme inhibitor; ACHD, adult congenital heart disease; ARB, angiotensin receptor blocker; CHD, congenital heart disease; NYHA, New York Heart Association.

findings, we hypothesized that these particular patients' unique psychosocial functioning would affect their mental health directly or indirectly.

Identification of the psychosocial factors that influence patients' mental health would enable medical personnel and others around them to better understand how to support them in attaining more stable mental health.

Therefore, the aims of this study were (1) to describe aspects of the psychosocial functioning of ACHD patients in Japan; and (2) to determine the psychosocial factors influencing their mental health.

## Methods

### Participants

Outpatients were recruited at Chiba Cardiovascular Center in Chiba Prefecture. The inclusion criteria were (1) presence of CHD and medical records that can be reviewed; (2) ability to

Table 2. Congenital Cardiac Diagnosis	
	n=72
<b>Simple CHD</b>	n=13
Isolated small ASD/VSD	6
Repaired ASD/VSD	4
Isolated aortic valve disease	2
Other simple defects	1
<b>CHD of moderate severity</b>	n=39
Tetralogy of Fallot	17
VSD with any valve problems and/or obstruction	4
Ebstein's anomaly	4
Atrioventricular canal/septal defects	3
Marfan syndrome	3
Other defects of moderate severity	8
<b>CHD of great complexity</b>	n=20
Congenitally corrected transposition of the great arteries	5
Transposition of the great arteries	4
Tricuspid atresia	4
Asplenia syndrome	2
Pulmonary atresia (all forms)	2
Truncus arteriosus	2
Other defects of great complexity	1

ASD, atrial septal defect; CHD, congenital heart disease; VSD, ventricular septal defect.

read and complete the consent form and questionnaire written in Japanese; and (3) age in the range 18–39 years.

The control group consisted of 86 participants (41 male, 45 female) who were either enrolled in a local seminar or who were guardians of students at local schools. (The age range in 36 was 18–29 years, and that in 51 was 30–39 years.)

### Procedure

This study received ethics approval from the Institutional Review Board. The purpose of the study and the privacy protection policy were explained to patients both verbally and in writing. Informed consent was obtained from each patient. The questionnaire was given to patients while they were receiving outpatient treatment at the hospital and their responses were collected immediately.

### Assessment of Psychosocial Functioning

The following 4 scales were administered.

**Independent-Consciousness Scale** This scale measures the transition from dependence to independence in the adolescent.<sup>19</sup> For the study, a total of 10 items was selected on 2 subscales: Independence (the ability to make one's own decisions regarding his/her future and any difficulties encountered) and Dependence on Parents (dependence on parents resulting from an inability to make one's own decisions and the sense of security obtained by being with parents). We used a 5-point rating scale, which was based on the original version (as were all subsequent rating procedures), and calculated an average for each subscale.

**Problem-Solving Inventory** This is a measure of social skills for effectively solving problems encountered in daily life.<sup>20</sup> We used a Japanese translation of a scale created by Heppner and Petersen, whose original version consisted of 32 items, but we reduced the number of items by using factor analysis to reduce the burden on the subjects. This factor

Psychosocial factors	ACHD	Control	P-value
Independent consciousness			
Independence	3.46±0.72	3.71±0.58	0.018
Dependence on parents	3.12±0.87	2.83±0.90	0.048
Problem-solving inventory	3.61±0.64	3.90±0.70	0.008
Locus of control	2.73±0.42	2.84±0.39	NS
Self-esteem	2.98±0.75	3.40±0.65	<0.001

Data given as mean±SD. ACHD, adult congenital heart disease.

SF-36	ACHD	Japanese normative data	P-value
Physical functioning	91.1±9.6	94.8±8.8	<0.001
Role physical	87.3±19.0	91.9±17.2	0.031
Bodily pain	79.6±22.6	76.8±22.2	NS
General health	61.1±17.3	66.5±18.8	0.019
Vitality	58.8±20.4	60.6±19.7	NS
Social functioning	85.1±19.2	86.7±18.4	NS
Role emotional	84.3±18.9	88.5±18.6	NS
Mental health	66.2±21.9	69.8±18.9	NS
MCS	47.8±10.2	48.2±8.5	NS

Data given as mean±SD. Age range for the Japanese normative data, 20–39 years.

ACHD, adult congenital heart disease; MCS, Mental Component Summary; SF-36, 36-item Short Form Health Survey.

analysis (maximum likelihood method, varimax rotation) used data obtained from 177 undergraduate students, and we ultimately selected and used a total of 14 items. The correlation coefficient for the shortened version and the original version was 0.959, which proved that the shortened version also has a high reliability. This scale was rated on a 6-point scale; the Problem-Solving Inventory (PSI) score was calculated by averaging the 14 items.

**Locus of Control Scale** This is a measure of the control of factors incidental to one's own actions and the results of those actions.<sup>21</sup> This scale included a total of 18 items rated on a 4-point scale on 2 subscales: Internal Control (the idea that one's actions can be controlled by oneself) and External Control (the idea that one's actions are controlled by external factors). This Locus of Control score was calculated by adding the average scores on Internal Control and the average of inverted scores on External Control. A higher score represents a stronger tendency toward internal control.

**Self-Esteem Scale** This is a measure of self-esteem, self-valuation, and the evaluation of one's own abilities.<sup>22,23</sup> We used a Japanese translation of a scale created by Rosenberg.<sup>23</sup> This score is calculated by averaging 10 items rated on a 5-point scale.

### Assessment of Mental Health

As a measure of mental health, we used the Mental Component Summary (MCS) of the Japanese version of the 36-item Short Form Health Survey (SF-36),<sup>24</sup> which is a generic measure of the health-related quality of life (QoL) and a well-validated instrument. It consists of 8 subscales (Physical Functioning, Role Physical, Bodily Pain, General Health, Vitality, Social Functioning, Role Emotional, and Mental Health), and higher scores reflect better perceived health status. This scale was used only for the ACHD group.

### Statistical Analysis

Data analyses were conducted using SPSS version 17.0 for Windows (SPSS Japan, Tokyo, Japan). Psychosocial functioning was analyzed by (1) using 1-way ANOVA to conduct comparisons between the subgroups with different degrees of cardiac defects in the ACHD group; and (2) using a t-test to compare the ACHD group and the control group. Next, mental health and QoL were analyzed by (1) using 1-way ANOVA to conduct comparisons between the subgroups with different degrees of cardiac defects in the ACHD group; and (2) performing a t-test to compare the ACHD group to Japanese normative data. Finally, a structural equation model was developed using SPSS-Amos (version 17.0) to investigate the psychosocial mechanisms that determine mental health. Model fit was evaluated using the most frequently reported fit indices:<sup>25,26</sup> (1) chi-square test (chi-square should be non-significant for a good fit); (2) root mean square error of approximation (RMSEA; values <0.06 are acceptable fit); (3) comparative fit index (CFI; values >0.95 are a good fit); and (4) standardized root mean square residual (SRMR; values <0.10 are acceptable fit). The significance level was set at P<0.05 for all analyses.

## Results

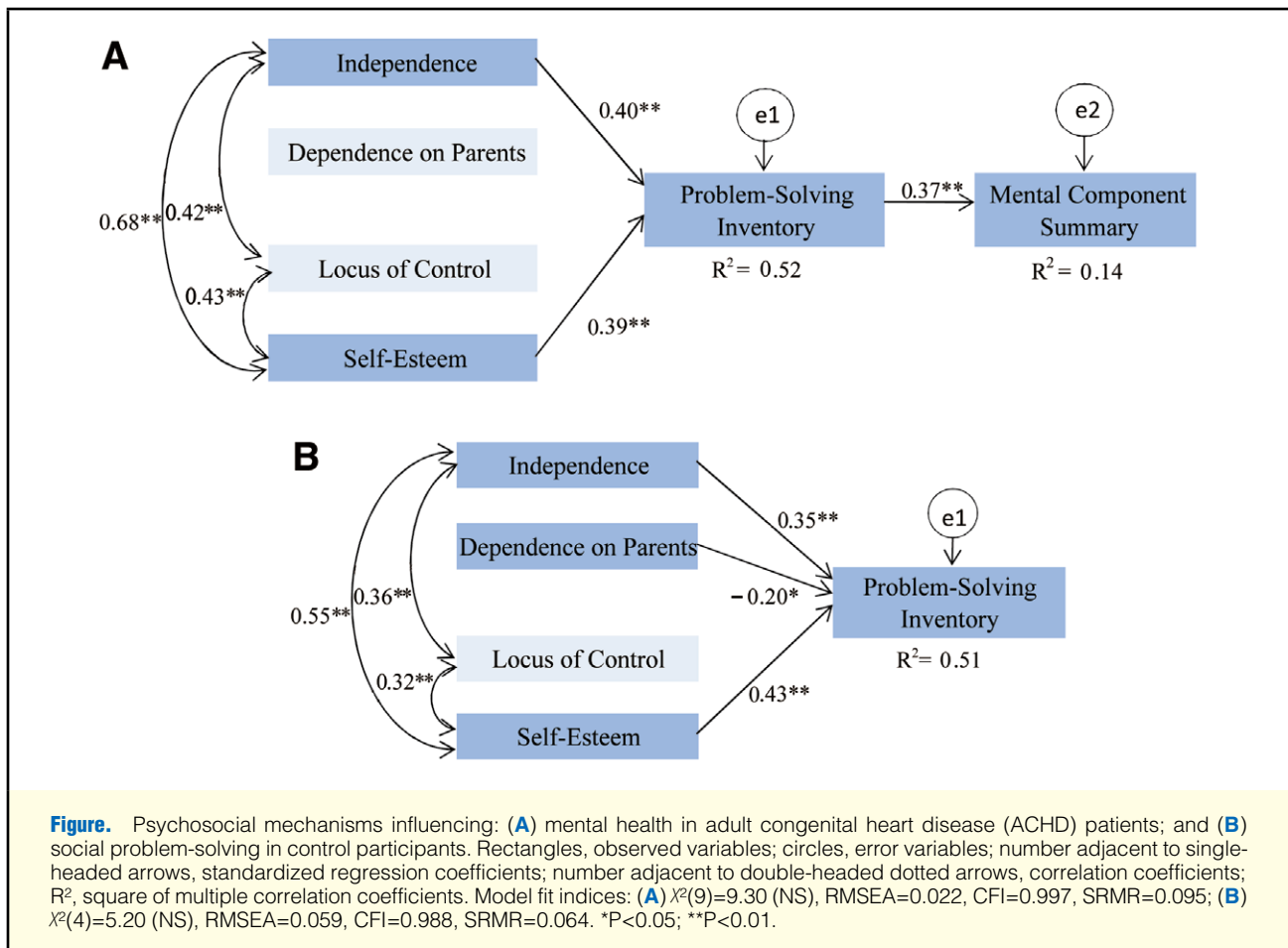
### Patient Characteristics

A total of 81 ACHD patients were approached in the outpatient clinic for study participation. Of those, 72 consented to participate and completed questionnaires. **Table 1** lists the demographic and medical characteristics of the ACHD group. **Table 2** lists the most common cardiac defects classified as simple, moderate, or great complexity, consistent with definitions from the 2008 ACC/AHA ACHD Guidelines.<sup>5</sup>

	1	2	3	4	5	6
1. MCS	–					
2. Independence	0.29*	–				
3. Dependence on parents	–0.24*	–0.12	–			
4. Problem-solving inventory	0.37**	0.65**	–0.19	–		
5. Locus of control	0.15	0.42**	–0.18	0.41**	–	
6. Self-esteem	0.36**	0.68**	–0.19	0.65**	0.42**	–

\*P<0.05; \*\*P<0.01.

ACHD, adult congenital heart disease; MCS, Mental Component Summary.



### Psychosocial Functioning

In comparisons among cardiac defect subgroups, analysis of psychosocial functioning in relation to diagnosis of cardiac defects showed no significant differences on any scale.

Descriptive statistics for the ACHD and control groups on each scale and t-test results are given in Table 3. Compared to the control group, the ACHD group had a significantly lower score on Independence and a significantly higher score on Dependence on Parents. Moreover, the ACHD group had significantly lower PSI and Self-Esteem. The group tended to have low independent consciousness, low social skills for problem-solving, and low self-confidence.

### Mental Health

Analysis of the 8 subscales of the SF-36 and MCS with regard to diagnosis of cardiac defects showed significant differences in Physical Functioning (simple=97.7, moderate=91.3, great=86.4; P<0.01) and General Health (simple=62.9, moderate=64.7, great=52.3; P<0.05). Post-hoc comparisons showed that defects of moderate and of great complexity were associated with significantly lower scores than those of simple complexity on Physical Functioning, and patients with defects of great complexity scored significantly lower than those with defects of moderate complexity on General Health.

Comparison of the ACHD group to Japanese normative data (people aged 20–39 years) on the SF-36 subscales and MCS showed the ACHD group to be significantly lower than

Japanese normative data on Physical Functioning, Role Physical, and General Health subscales. There were no significant differences, however, in mental health (Table 4).

### Psychosocial Mechanisms That Influence Mental Health

To examine the relationship between psychosocial factors and MCS in the ACHD group, we first calculated correlation coefficients between each scale and the MCS (Table 5). An examination of psychosocial factors relevant to MCS indicated weak correlations between them, except for Locus of Control.

Using a structural equation model, we tested models in which psychosocial factors affect mental health in parallel or through mediator variables. After testing several models, we established that the best fit was provided by a mediation model that used PSI as a mediator variable ( $\chi^2(9)=9.30$  (NS), RMSEA=0.022, CFI=0.997, SRMR=0.095). The final model is shown in Figure A. Given that MCS was not measured in the control group, the results for the same model excluding MCS are shown in Figure B.

In the ACHD group, it was found that Independence and Self-Esteem had positive influences on PSI, and that PSI then had a positive influence on MCS. Moreover, it was demonstrated that in the control group, Independence and Self-Esteem had positive influences on PSI, whereas Dependence on Parents had a negative influence.

Furthermore, it was found that Independence and Self-Esteem were highly correlated in both the ACHD and control groups.

## Discussion

### Psychosocial Functioning

The ACHD group had lower scores on Independence, PSI, and Self-Esteem and a higher score on Dependence on Parents compared to the control group. It seems that CHD patients in Japan have psychosocial difficulties in adulthood.

Previous interview studies have indicated that in relationships with parents, adolescent and adult CHD patients tend to depend on their parents due to overprotection, and hence, they have low independent consciousness.<sup>17–18</sup> In questionnaire studies that asked adolescent patients about their relationships with their parents, the patients evaluated their parents to be warmer, more accepting, and less controlling than did the control group.<sup>27</sup> In considering all these results, it seems that adolescent patients are dependent on and mostly free of conflict with their parents. In contrast, the longitudinal study by Utens et al reported that the proportion of patients living with their parents was higher than that of the same-generation reference group when the average age of the subjects was 22.7,<sup>7</sup> although the proportions had equalized at an average age of 30.2.<sup>9</sup> These results indicate that even though the patients are reliant on their parents, it is possible for them to move gradually toward independence, albeit slightly later than people of the same age. The most important need is to encourage a form of independence that suits each patient while balancing out their dependence on those around them.

The ability to solve social problems was low in this patient group, but because this factor has rarely been examined in previous studies, it is unknown whether patients in countries other than Japan would also have low scores. Social problem-solving is the process of comprehending and solving problems that occur in daily life.<sup>28</sup> Low social problem-solving ability means that patients more frequently experience difficult situations in which they are unable to solve the problems they encounter daily, which could diminish mental health.

Furthermore, the ACHD group scored low in self-esteem. They lack confidence and do not have positive feelings toward themselves. Moreover, Utens et al studied self-esteem in the Netherlands; nevertheless, they found that, if anything, adult patients have better results than the reference group.<sup>7,9</sup> Those studies, however, used a different scale to measure self-esteem. Studies of adolescent patients that used the Rosenberg scale, as in the present study, have demonstrated either that there is no difference between them and the reference group,<sup>29</sup> or that only patients with severe disease have low self-esteem.<sup>30</sup> The former study was conducted in the USA and the latter was conducted in Israel. These studies thus reported that patients in general have average self-esteem; patients in Japan, however, have comparatively low self-esteem.

There was no difference in Locus of Control scores between the patient and control groups: patients perceive the causes and effects of their actions in the same manner as the control group, even if they have a disease. Because their disease is congenital and chronic, living with illness is normal for these patients; therefore, they have the same feelings of control over their life events as the healthy group.

### SF-36 Mental Health

On the SF-36 subscales and MCS, significant differences among cardiac defect diagnoses were observed only in the subscales related to physical and health factors: the more severe the disease, the sharper the decline in QoL related to these factors. We found, however, that mental health factors are not affected by CHD. Moreover, similar results were seen in comparisons between Japanese normative data and the ACHD group, demonstrating that having a disease, in itself, influences physical health but not mental health.

Various results have been reported from previous research on young adult and adult CHD patients using the SF-36. Their overall QoL was better compared to the normative data, and the severity of disease did not make any difference.<sup>31,32</sup> But ACHD patient scores have also been shown to be lower than the normative scores on some subscales.<sup>16,33</sup> Although these results are inconsistent, the lower subscale results obtained among ACHD patients are similar to the present results, in that the lower QoL was associated with physical and health factors. Therefore, disease influences QoL mainly in relation to physical health, and patients live in fear of their health. It is necessary for parents and medical personnel to explain physical and health aspects firmly to patients so that they do not experience more anxiety than their actual health situation warrants.

Furthermore, patients' mental health was similar to the Japanese normative data. This result was observed also in previous studies, which used SF-36 MCS and were conducted outside Japan.<sup>31,34</sup> The mental health aspect of QoL refers not to any specific mental symptoms but to overall mental health. Therefore, it is possible that the present findings did not fully reflect patients' psychiatric condition.

### Psychosocial Mechanisms That Influence Mental Health

It was found that the most influential psychosocial factor on patients' mental health is the ability to solve social problems that directly affect their mental health. The patient group, however, had lower social problem-solving ability than the control group. We can conclude from this that patients falter easily in problem-solving situations, and that they are at risk of suffering a decline in their mental health. Moreover, social problem-solving ability is considered a life skill or social skill that is learned through direct or vicarious experiences with parents or

other adults.<sup>28</sup> A dearth of opportunities to learn social skills could be the reason for patients' low social problem-solving ability. In this case, patients might also have difficulty in acquiring age-appropriate general social skills, in addition to social problem-solving abilities.

Overall, 14% of the variance in MCS could be explained by the model. Other factors, such as other social skills and social support, indicated much more variance in the patients' mental health. Further study is needed to look at how these components contribute to overall mental health.

From the present results, it is obvious that what these patients need for solving social problems is both a sense of independence and of self-esteem. Social problem-solving ability can be cultivated by appropriately developing these characteristics. Because patients perform worse than the control group in these 2 areas, however, it is difficult for them to maintain mental health. It is necessary to first consider measures for fostering independence and self-esteem while taking into consideration developmental stage.

A comparison between the patient and control groups in psychosocial factors that influence social problem-solving showed that although Dependence on Parents was negatively associated with social problem-solving in the control group, there was no such association in the patient group; rather, only Independence was positively associated with social problem-solving, as it was in the control group as well. In other words, a strong sense of self is important for patients regardless of their dependence on their parents. There are many cases in which ACHD patients require support from others because of their condition. The present results show that patients depend on their parents more than the control group do, and that their parents' existence is a major source of support for them even in adulthood. It is important for patients to have a strong sense of self, using their parents as support, and to mature into adults with independent decision-making abilities. To that end, parents and medical personnel should support children with CHD in such a way as to help them become functional in society and also encourage them to become thoroughly familiar with their disease, so that they can effectively manage their medication and physical condition as adults.

### Study Limitations

First, the present study used a cross-sectional design. If a longitudinal study were designed, it would be possible to present a definite association between psychosocial factors and mental health. Next, this study was conducted with patients under regular care at an ACHD center; therefore these results cannot be generalized to patients who were lost to follow-up or who are not currently engaged in regular CHD follow-up at a specialized center. In addition, the number of patients enrolled in this study was small, but the overall response rate in this study was approximately 90%. For this reason, we believe that these results reflect the characteristics of patients being followed up at a specialized center.

### Conclusion

Psychosocial factors influencing ACHD patients' mental health are social problem-solving, independence, and self-esteem. Patients, however, have poorer abilities than people of the same age in all of these areas. This indicates that the development and maintenance of patients' mental health in daily life is fraught with difficulty in Japan. Additionally, it was shown that independence and self-esteem influence social problem-solving, which in turn determines mental health, and it is pos-

sible that patients' psychosocial characteristics lead to a chain reaction that gives rise to further problems. In other words, to have CHD means to have an inborn risk factor for psychosocial development.

It is necessary in future to identify the psychological and social factors that determine negative mental health from a psychosocial mechanistic perspective and to offer multiple viewpoints on specific support from a preventative perspective, while continuing to increase the evidence base.

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