



# Objective and Personalized Assessment of Disease-Related Knowledge Among Patients With Congenital Heart Disease

## — Development and Validation of the Japanese Version of the Leuven Knowledge Questionnaire for Congenital Heart Disease —

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**Background:** Disease understanding in patients with congenital heart disease is important in transitional and lifelong care. This study aimed to develop the Japanese version of the Leuven Knowledge Questionnaire for Congenital Heart Disease (LKQCHD) and identify factors associated with disease-related knowledge.

**Methods and Results:** After confirming the content and face validity of the scale, a questionnaire including the LKQCHD was distributed to 59 eligible patients aged >16 years attending a university hospital. For the 58 participants who responded (30 males, 28 females; median age 22 years), the mean ( $\pm$ SD) LKQCHD total score was  $53.7\pm 15.4$ , with mean ( $\pm$ SD) scores for each domain as follows: Disease and Treatment,  $68.3\pm 19.7$ ; Preventing Complications,  $45.8\pm 19.0$ ; Physical Activity,  $74.1\pm 34.1$ ; Sex and Heredity,  $37.9\pm 35.4$ ; and Contraception and Pregnancy,  $40.2\pm 29.1$ . Regarding known-groups validity, we found a positive correlation between the LKQCHD score and age ( $\rho=0.268$ ,  $P=0.042$ ), and a significantly low LKQCHD score in the moderate/severe disease group ( $\eta^2=0.131$ ,  $P=0.021$ ). Regarding convergent validity, the LKQCHD score was positively correlated with the total and subscale scores of the Resilience Assessment Tool ( $r=0.213$  [ $P=0.109$ ] and  $r=0.405$  [ $P=0.002$ ], respectively).

**Conclusions:** We confirmed the validity of the Japanese version of the LKQCHD, concluding that patient education regarding long-term complications, prevention methods, heredity, pregnancy, and childbirth is needed.

**Key Words:** Congenital heart disease; Disease knowledge; Japan; Transitional care; Young adult

Medical advances have reduced infant mortality in patients with congenital heart disease (CHD),<sup>1</sup> and many now reach adulthood. In Japan, there were 400,000 patients with adult CHD (ACHD) in 2007, and this number has been increasing by 9,000 every year.<sup>2</sup> Patients with ACHD are at a high risk of cardiovascular problems,<sup>3</sup> with 77% of deaths due to cardiovascular causes,<sup>4</sup> thus necessitating self-care and frequent medical checkups.

Transition is a lifelong process that seeks to meet the individual care needs of young adults with special health-care needs and involves transferring from a pediatric to an adult care professional.<sup>5</sup> The transition process requires preparing young people to transfer to adult care, receiving

age-appropriate education about medical conditions, and promoting communication, decision making, self-care, and self-advocacy.<sup>6</sup> Successful transfer is related to patients' better disease-related knowledge, health status, and autonomy.<sup>7</sup> Of these, disease-related knowledge has been evaluated in numerous studies, with CHD/ACHD patients shown to have limited knowledge.<sup>8</sup> Furthermore, previous studies showed that disease-related knowledge can be improved by transitional care programs.<sup>9–12</sup> In all these studies, patients' disease-related knowledge was evaluated objectively.

The Leuven Knowledge Questionnaire for Congenital Heart Disease (LKQCHD), developed by Moons et al,<sup>13</sup> is a tool for measuring disease-related knowledge in patients

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with CHD. The LKQCHD asks specific questions about the disease and responses are evaluated by healthcare professionals, thereby allowing for an objective and personalized evaluation of knowledge. The LKQCHD has been translated into many languages and is widely used internationally.<sup>14,15</sup> However, a Japanese version of the LKQCHD has not yet been developed, and no studies have objectively investigated disease-related knowledge among CHD patients in Japan. Therefore, the aim of this study was to develop the Japanese version of the LKQCHD that could objectively assess the disease-related knowledge of CHD patients and identify the factors associated with such knowledge.

## Methods

This was a cross-sectional study using a self-administered questionnaire and review of medical records. The study period was from July to October 2020.

### Study Population

Participants were patients with CHD attending a university hospital in the Kanto region of Japan. The hospital has a pediatric cardiology outpatient clinic and an ACHD specialized outpatient clinic directed by a cardiologist. Inclusion criteria patients had to be  $\geq 16$  years of age, diagnosed with CHD before birth, in infancy, or while of school age, and have the ability to answer the questionnaire by themselves. Patients with developmental delay and who had difficulty answering the questionnaire by themselves, those judged by the attending physician to be mentally unstable, or those who had difficulty participating in the survey were excluded.

### Measurements

The Japanese version of the LKQCHD was developed based on the UK version of the LKQCHD (original LKQCHD), with permission from the original author. The original LKQCHD consists of 5 domains: (1) Disease and Treatment; (2) Preventing Complications; (3) Physical Activity; (4) Sex and Heredity; and (5) Contraception and Pregnancy.<sup>16</sup> The domain of Contraception and Pregnancy is only for females; thus, the questionnaire has 25 items and 31 questions for males and 27 items and 34 questions for females. For the Japanese version of the LKQCHD, we evaluated each participant's answers as "correct", "does not know", "incorrect", and "incomplete" by referring to the LKQCHD UK version 2009 coding manual. Correct answers varied depending on the individual's clinical condition; therefore, the answers were assessed based on the judgment of the attending physician and a review of the medical records.

### Development and Validation of the Japanese Version of the LKQCHD

For the Japanese version of the LKQCHD, content validity, face validity, known-groups validity, and convergent validity<sup>17</sup> were evaluated. Reliability was not examined because the LKQCHD includes various content items related to the disease and because disease-related knowledge varies over time and depends on the patient's growth.

The translation protocol involved forward and backward translation. Three researchers (2 nurses, 1 psychologist) who were native Japanese speakers and knowledgeable about CHD conducted the forward translation indepen-

dently, and the Japanese translation was finalized through consensus. Back-translation was performed by a native English speaker who was not familiar with CHD. The back-translated version was reviewed and approved by the original author.

A content validity evaluation was conducted by 6 healthcare providers involved in CHD care: pediatric cardiologists who are board-certified members of the Japanese Society of Pediatric Cardiology and Cardiac Surgery, a pediatric cardiologist and a surgeon who are board-certified members of the Japanese Society for Adult Congenital Heart Disease, 2 certified nurse specialists in child health nursing, and 1 certified nurse in pediatric emergency nursing. The content validity index (CVI) was used to evaluate content validity.<sup>18</sup> The CVI enables quantitative evaluation of scales. Using a 4-point scale (ranging from 1=not relevant to 4=very relevant), the relevance of the questionnaire content on disease-related knowledge of CHD patients was assessed. Opinions were obtained through open-ended responses regarding items that were considered difficult to answer and items that needed improvement and alternatives. A score of 1 was assigned to "relevant" and "fairly relevant", whereas a score of 0 was assigned to "not relevant" and "slightly relevant", and the item CVI was calculated by dividing the score for each questionnaire item by the number of raters. The scale CVI was calculated by averaging the item CVIs. The cut-off points for the CVI were  $\geq 0.78$  for the item CVI and  $\geq 0.9$  for the scale CVI/average.<sup>19</sup> Finally, the Japanese version of the LKQCHD had an item CVI of  $>0.78$ , and a scale-CVI/average of 0.98, thus showing content validity.

Based on open-ended responses obtained during content validity evaluation, the following 6 items of the LKQCHD were modified in consideration of the study's Japanese context.

1. The following diagnoses were added to the list of diseases based on the registration information of the Japanese Network of Cardiovascular Departments for ACHD:<sup>20</sup> congenitally corrected transposition of the great arteries, single ventricle/univentricular heart, atrioventricular septal defect/endocardial cushion defect, and bicuspid aortic valve.
2. The options for the frequency of outpatient visits were changed because most CHD patients in Japan visit the outpatient clinic at least once a year.
3. In the question on previous treatment, the catheterization option was revised to balloon dilation, stenting, coil embolization, or device therapy.
4. Regarding medications, side effects and interactions were removed because they were not used in the evaluation.
5. Because "endocarditis" is commonly referred to as "infective endocarditis", the term was changed accordingly.
6. The question about contraceptive methods was revised to include the most common contraceptive methods in Japan.

Modifications and additions to the questions and choices were made with the approval of the original author.

For face validity, 6 participants were recruited to answer the Japanese version of the LKQCHD. We asked participants whether there were any items on the questionnaire that were difficult to understand or answer. No issues were raised regarding the content of the questions or items. The mean time required to answer the questionnaire was 10.7 min

(range 7–13 min), and there were no missing responses. Therefore, the Japanese version of the LKQCHD was considered to have face validity.

We developed the Japanese version of the LKQCHD, comprising 25 items and 31 questions for males and 27 items and 35 questions for females. Thereafter, known-groups validity and convergent validity were tested quantitatively for the following 4 hypotheses:

Hypothesis 1: older patients have higher LKQCHD total scores

Hypothesis 2: there are group differences in LKQCHD total scores due to disease severity

Hypothesis 3: patients with higher scores on the Assessment Tool to Measure the Resilience Related to Illness Experiences in School-aged Children, Adolescents and Young Adults with Congenital Heart Disease<sup>21</sup> (hereafter, “Resilience Assessment Tool”) have higher LKQCHD total scores

Hypothesis 4: Patients with higher scores on the Factor 1 subscale score of the Resilience Assessment Tool have higher LKQCHD total scores.

The Resilience Assessment Tool was originally developed by Nio et al and shown to have validity and reliability.<sup>21</sup> Resilience is an interactive concept that refers to one’s

relative resistance to environmental risk experiences, or the overcoming of stress or adversity,<sup>22</sup> and is influenced by early life experiences that happen during childhood and adolescence.<sup>23</sup> Factor 1 of the scale is “I can understand my illness”, which consists of 4 items: “I can explain my illness by changing the content of my explanation to suit the listener”, “I can explain my illness to friends and other people”, “I am knowledgeable about my illness”, and “I can understand the doctor’s explanations”. These items assess self-reported disease-related knowledge of patients with CHD. Therefore, the Resilience Assessment Tool was used to assess convergent validity with the permission of the author.

### Data Collection

Participants were approached after their outpatient visit, and a researcher explained the research both verbally and in writing. Thereafter, the questionnaire was distributed to participants who consented to take part in the study. The participants were requested to not refer to any other material when answering the questionnaire and to deposit their completed questionnaire in a box.

The questionnaire included background information, the Japanese version of the LKQCHD, and the Resilience Assessment Tool for convergent validity assessment. Items

<b>Table 1. Demographic and Clinical Characteristics of Patients With Congenital Heart Disease (n=58)</b>		
	<b>No. patients (%)</b>	<b>Mean (±SD) total LKQCHD score</b>
<b>Median [IQR] age (years)</b>	22 [18–32]	53.7±15.4
<b>Sex</b>		
Male	30 (51.7)	55.2±15.5
Female	28 (48.3)	52.0±15.4
<b>Department</b>		
Pediatrics	40 (69.0)	51.9±16.6
Cardiology	18 (31.0)	57.6±11.8
<b>Frequency of follow-up</b>		
Once a year	17 (29.3)	54.9±15.3
Once every 4–6 months	9 (15.5)	48.9±13.3
More than once every 3 months	32 (55.2)	54.3±16.2
<b>Disease severity</b>		
Mild	5 (8.6)	71.4±7.5
Moderate	24 (41.4)	53.0±14.0
Severe	29 (50.0)	51.1±15.9
<b>History of endocarditis</b>		
No	55 (94.8)	53.9±14.8
Yes	3 (5.2)	49.4±28.4
<b>Pacemaker or ICD implantation</b>		
No	52 (89.7)	52.6±15.8
Yes	6 (10.3)	62.9±6.2
<b>Hospitalization within 1 year</b>		
No	52 (89.7)	54.2±15.6
Yes	6 (10.3)	48.7±13.8
<b>History of gravidity<sup>A</sup></b>		
No	26 (92.9)	54.0±14.0
Yes	2 (7.1)	27.1±14.1
<b>History of loss to follow-up</b>		
No	53 (91.4)	53.8±16.0
Yes	5 (8.6)	52.0±8.0

(Table 1 continued the next page.)

	No. patients (%)	Mean ( $\pm$ SD) total LKQCHD score
<b>Educational background<sup>B</sup></b>		
High school or less	28 (49.1)	49.4 $\pm$ 14.1
Associate degree	13 (22.8)	52.5 $\pm$ 17.2
Bachelor degree or above	16 (28.1)	61.7 $\pm$ 14.2
<b>Individuals accompanying patients</b>		
With parents	29 (50.0)	49.2 $\pm$ 14.6
Alone	25 (43.1)	57.3 $\pm$ 15.6
With siblings or spouse	4 (6.9)	63.0 $\pm$ 12.9
<b>Individuals communicating with doctors during the outpatient examination</b>		
Patient himself/herself	52 (89.7)	55.2 $\pm$ 15.4
Parents	6 (10.3)	40.7 $\pm$ 7.8
<b>Parents have told me the name of the disease</b>		
Yes	53 (91.4)	54.8 $\pm$ 14.9
No	5 (8.6)	41.4 $\pm$ 16.7
<b>My doctor has told me the name of the disease</b>		
Yes	53 (91.4)	54.3 $\pm$ 15.6
No	5 (8.6)	46.8 $\pm$ 13.1
<b>Forgetting to take medication</b>		
No medicine	25 (43.1)	53.5 $\pm$ 14.9
No	15 (25.9)	53.2 $\pm$ 17.3
1–3 times per month	11 (19.0)	55.2 $\pm$ 13.8
1–2 times per week	3 (5.2)	54.1 $\pm$ 32.0
$\geq$ 3 times per week	4 (6.9)	51.7 $\pm$ 5.0
<b>Receive a dental checkup once a year<sup>B</sup></b>		
Yes	30 (52.6)	55.2 $\pm$ 17.7
No	27 (47.4)	52.6 $\pm$ 12.5
<b>Subjective cardiac symptoms</b>		
Yes	14 (24.1)	57.8 $\pm$ 12.9
No	44 (75.9)	52.4 $\pm$ 16.1
<b>Need lifelong cardiac care from a cardiologist</b>		
Yes	42 (72.4)	55.9 $\pm$ 15.6
No	0 (0.0)	–
I don't know	16 (27.6)	47.8 $\pm$ 13.9

<sup>A</sup>n=28 (only female patients). <sup>B</sup>n=57. ICD, implantable cardioverter-defibrillator; IQR, interquartile range; LKQCHD, Leuven Knowledge Questionnaire for Congenital Heart Disease.

for background information were selected based on previous studies<sup>24–28</sup> and discussions among researchers. The severity of CHD was assessed using the criteria of the Guidelines for Management of Congenital Heart Diseases in Adults (JCS 2017).<sup>29</sup>

### Statistical Analysis

Descriptive statistics were used for participants' demographic data and the distribution of LKQCHD responses. The LKQCHD UK version 2009 coding manual was followed, with some modifications. The percentage of correct answers provided by the participants was categorized into adequate (>80%), moderate (50–80%), and poor knowledge (<50%).

The LKQCHD total score (range 0–100) and subscale scores for each of the 5 domains were calculated by dividing the number of correct responses by the number of questionnaire items and multiplying by 100. The total score indicates a respondent's level of disease-related knowledge and was used to test each hypothesis. For Hypotheses 1, 3, and 4, Pearson's correlations or Spearman's rank correla-

tions were used depending on the distribution of variables, whereas 1-way analysis of variance (ANOVA) was used for Hypothesis 2.

In addition, we explored contextual factors affecting disease-related knowledge using linear regression analysis. A single regression analysis was conducted with the contextual factors as independent variables and the LKQCHD total score as the dependent variable. Multiple regression analysis was conducted using the forced entry of variables with an F-value of  $\geq 2$  as independent variables.

Data were analyzed using SPSS version 27.0 (SPSS Inc., Chicago, IL, USA), and statistical significance was defined as 2-tailed  $P < 0.05$ .

### Ethical Considerations

The research was conducted in accordance with the Declaration of Helsinki. We explained to the participants, both verbally and in writing, the study's purpose and our privacy policy, and that their participation was not mandatory and could be withdrawn at any time. Written consent was obtained from all participants.

<b>Table 2. Frequency Distribution of the Japanese Version of the Leuven Knowledge Questionnaire for CHD (n=58)</b>			
	<b>% Correct (95% CI)</b>	<b>Does not know (%)</b>	<b>Incorrect or incomplete (%)</b>
<b>Disease and Treatment</b>			
1. What is the exact name of the type of heart disease you have?	81.0 (70.7–89.7)	12.1	6.9
2. Explain where your heart is affected below either by describing in words or drawing on the diagram	48.3 (36.2–62.1)	29.3	22.4
3. How often do you need to visit the hospital for a follow-up observation concerning your heart disease?	94.8 (87.9–100.0)	0.0	5.2
4. What is the main purpose of the follow-up observations?	75.9 (63.8–87.9)	0.0	24.1
5. What treatment have you received for your heart so far?	58.6 (44.9–70.7)	3.4	38.0
6. If you are taking medicine, please provide the name of the medicine and benefits (n=33)	39.4 (23.3–56.4)	3.0	57.6
7. Should you stop taking a medicine if you begin experiencing side effects? (n=56)	69.6 (57.1–82.1)	16.1	14.3
8. Are you required to restrict your diet? (n=57)	93.0 (85.7–98.2)	0.0	7.0
9. Select all symptoms that could suggest the condition of your heart has worsened and you need to contact your physician	15.5 (6.9–25.9)	22.4	62.1
10. If your physician has said there is no problem, does that mean there is no need for any follow-up observations?	84.5 (74.1–93.1)	8.6	6.9
Domain correct answer rate (mean ± SD)	68.3±19.7		
<b>Preventing Complications</b>			
11. What is infective endocarditis?	41.4 (29.3–55.1)	55.2	3.4
12. What are the main symptoms and typical symptoms of infective endocarditis?	3.4 (0.0–8.6)	74.1	22.4
13. Can you only have infective endocarditis once in your life?	29.3 (17.2–41.4)	69.0	1.7
14. Do you think these are involved in the development of infective endocarditis?			
Reusing medicine (drug) users' needles (n=57)	61.4 (49.1–73.7)	33.3	5.3
Smoking (n=57)	24.6 (14.0–36.8)	33.3	42.1
Bacteria from a skin infection	48.3 (34.5–60.3)	39.7	12.1
Swelling and pus in your gums	65.5 (53.4–77.5)	31.0	3.4
Sexual activity (n=55)	16.4 (7.3–25.5)	58.2	25.5
Not looking after your skin and nails properly (n=57)	21.1 (12.3–31.6)	52.6	26.3
Piercings and tattoos (n=57)	42.1 (29.8–54.4)	42.1	15.8
15. Should you immediately take antibiotics if you begin to have a fever without discussing it with your doctor?	65.5 (53.4–77.6)	20.7	13.8
16. Should you have a dental checkup at least once a year? (n=57)	73.7 (61.4–84.2)	21.1	5.3
17. Should you always take antibiotics before going to the dentist?	58.6 (44.8–72.4)	31.0	10.3
18. Do you need to be particularly careful about bleeding from the gums?	53.4 (41.4–65.5)	22.4	24.1
19. Should you brush your teeth at least once a day?	100.0 (100.0–100.0)	0.0	0.0
20. Is smoking more harmful to people with CHD than others?	6.9 (1.7–13.8)	10.3	82.8
21. Is drinking 3 or more alcoholic drinks a day more harmful to people with CHD than others?	72.4 (60.3–84.5)	22.4	5.2
Domain correct answer rate (mean ± SD)	45.8±19.0		
<b>Physical Activity</b>			
22. Can you participate in competitive sports (on a regional or national level) that require daily training?	69.0 (56.9–79.3)	13.8	17.2
23. Should you choose a job that is not too physically demanding because it's better not to overdo it?	79.3 (69.0–89.7)	12.1	8.6
Domain correct answer rate (mean ± SD)	74.1±34.1		
<b>Sex and Heredity</b>			
24. Is it fine for you to engage in all sexual activity of which you think yourself capable?	32.8 (20.7–44.8)	58.6	8.6
25. How high is the likelihood that your children will have CHD?	43.1 (31.0–56.9)	44.8	12.1
Domain correct answer rate (mean ± SD)	37.9±35.4		
<b>Contraception and Pregnancy (females only; n=28)</b>			
26. Considering you have CHD, which birth control method is most desirable?			
Condoms	75.0 (57.1–89.3)	25.0	0.0
The pill (oral contraceptive)	28.6 (14.3–46.4)	46.4	25.0
The coil (intrauterine contraceptive device)	14.3 (3.6–28.6)	75.0	10.7
27. Is there a risk of complications during pregnancy?	42.9 (25.0–64.3)	50.0	7.1
Domain correct answer rate (mean ± SD)	40.2±29.1		
<b>Total correct answer rate (mean ± SD)</b>	<b>53.7±15.4</b>		

CHD, congenital heart disease.

Study year	2001	2010	2011	2014	2020
Country and reference	Belgium <sup>13</sup>	Belgium <sup>16</sup>	Taiwan <sup>15</sup>	Korea <sup>14</sup>	Japan (present study)
Number of targets	61	91	89	40	58
Target age (years)	18–46	15–32	12–18	12–21	16–46
Questions	Correct answers (%)				
1. What is the exact name of the type of heart disease you have?	61.3	45.0	47.2	46.0	81.0
2. Explain where your heart is affected below either by describing in words or drawing on the diagram.	50.0	27.0	14.6	24.0	48.3
3. How often do you need to visit the hospital for a follow-up observation concerning your heart disease?	96.8	78.0	88.8	72.0	94.8
4. What is the main purpose of the follow-up observations?	48.4	46.0	58.4	34.0	75.9
5. What treatment have you received for your heart so far?	95.2	85.0	84.3	70.0	58.6 <sup>A</sup>
6. If you are taking medicine, give the name, dose, time, benefits, side-effect and interaction.	77.8	53.0	62.9	35.3	39.4
7. Should you stop taking a medicine if you begin experiencing side effects?	88.9	41.0	18.0	20.0	69.6
8. Are you required to restrict your diet?	98.4	94.0	84.3	48.0	93.0
9. Select all symptoms that could suggest the condition of your heart has worsened and you need to contact your physician.	30.6	9.0	13.5	14.0	15.5
10. If your physician has said there is no problem, does that mean there is no need for any follow-up observations?	98.4	87.0	80.9	62.0	84.5
11. What is infective endocarditis?	16.1	21.0	24.7	50.0	41.4
12. What are the main symptoms and typical symptoms of infective endocarditis?	8.1	1.0	3.4	10.0	3.4
13. Can you only have infective endocarditis once in your life?	51.6	14.0	9.0	30.0	29.3
14. Do you think these are involved in the development of infective endocarditis?					
Reusing drug users' needles	51.6	20.0	29.2	44.0	61.4
Smoking	32.3	8.0	16.9	12.0	24.6
Bacteria from a skin infection	35.5	11.0	21.3	16.0	48.3
Swelling and pus in your gums	71.0	22.0	24.7	36.0	65.5
Sexual activity	50.0	24.0	21.3	22.0	16.4
Poor skin and nail care	9.7	8.0	13.5	16.0	21.1
Piercings and tattoos	29.0	15.0	20.2	16.0	42.1
15. Should you immediately take antibiotics if you begin to have a fever without discussing it with your doctor?	83.9	78.0	57.3	68.0	65.5
16. Should you have a dental checkup at least once a year?	98.4	84.0	74.2	70.0	73.7
17. Should you always take antibiotics before going to the dentist?	83.9	78.0	55.1	42.0	58.6
18. Do you need to be particularly careful about bleeding from the gums?	88.7	75.0	68.5	62.0	53.4
19. Should you brush your teeth at least once a day?	96.8	96.0	93.3	94.0	100.0
20. Is smoking more harmful to people with CHD than others?		8.0	4.5	6.0	6.9
21. Is drinking 3 or more alcoholic drinks a day more harmful to people with CHD than others?	21.0	24.0	59.6	72.0	72.4
22. Can you participate in competitive sports (on a regional or national level) that require daily training?	71.0	39.0	55.1	38.0	69.0
23. Should you choose a job that is not too physically demanding because it's better not to overdo it?	88.7	75.0	39.3	60.0	79.3
24. Is it fine for you to engage in all sexual activity of which you think yourself capable?	69.4	78.0	27.0	18.0	32.8
25. How high is the likelihood that your children will have CHD?	25.8	20.0	13.5	26.0	43.1 <sup>A</sup>
26. Considering you have CHD, which birth control method is most desirable?					
The pill	80.0	35.0	12.2	0.0	28.6
The coil	26.7	14.0	18.4	12.5	14.3
27. Is there a risk of complications during pregnancy?	86.7	12.0	2.0	33.3	42.9 <sup>A</sup>

<sup>A</sup>The scoring method in this study has been partially changed from that in the original coding manual. CHD, congenital heart disease.

## Results

In all, 61 patients were approached in the outpatient clinic, of whom 59 consented to participate in the study and completed the questionnaire. One respondent did not meet the eligibility criteria because the researcher read and explained the questionnaire items as the respondent answered the questions; thus, responses from 58 patients were included in the analysis.

### Characteristics of Study Participants

**Table 1** presents the demographic characteristics of the participants. The median age of the participants was 22 years (interquartile range 18–32 years), and the sex ratio was approximately equal. Although 40 patients (69.0%) visited pediatric outpatient clinics, 18 (31.0%) visited cardiovascular outpatient clinics. Disease severity was mild in 5 patients (8.6%), moderate in 24 patients (41.4%), and severe in 29 patients (50.0%). Five patients (8.6%) reported a history of loss to follow-up.

Twenty-nine patients (50.0%) visited the outpatient clinic with their parents, 25 patients (43.1%) visited the clinic alone, and 4 patients (6.9%) visited with others. Six participants (10.3%) reported that their parents mainly talked with the doctor during the examinations. Five patients (8.6%) had never heard the disease name from their parents, and 5 (8.6%) had never heard the disease name from their doctors. Fourteen patients (24.1%) had subjective symptoms related to their cardiac condition, and 44 patients (75.9%) had no subjective symptoms. As to whether lifelong examination by the cardiologist is needed, 42 (72.4%) answered “necessary”, 16 (27.6%) answered “does not know”, and no one answered “not necessary”.

### Disease Knowledge of Patients With CHD

**Table 2** presents the frequency distribution of responses to the Japanese version of the LKQCHD and **Table 3** presents a comparison of the distribution of responses to the LKQCHD surveyed previously in other countries.

**LKQCHD Total and Domain-Specific Scores** The mean ( $\pm$ SD) LKQCHD total score was  $53.7\pm 15.4$ . Mean ( $\pm$ SD) domain-specific scores were as follows: Disease and Treatment,  $68.3\pm 19.7$ ; Prevention of Complications,  $45.8\pm 19.0$ ; Physical Activity,  $74.1\pm 34.1$ ; Sex and Heredity,  $37.9\pm 35.4$ ; and Contraception and Pregnancy (females only),  $40.2\pm 29.1$ .

**Disease and Treatment** The percentage of correct answers for the name of the heart disease was 81.0%, indicating adequate knowledge. However, only 48.3% of participants could describe the disease, which is categorized as poor knowledge. Participants were found to have moderate to adequate knowledge of the following: frequency of follow-up visits (94.8%), the purpose of follow-up (75.9%), history of treatment (58.6%), side effects (69.6%), diet restrictions (93.0%), and need for follow-up even without problems (84.5%). When 33 patients who took medications were asked about the name of the medication and its benefits, the correct answer rate was 39.4%, which represents poor knowledge. In addition, knowledge of heart failure symptoms caused by deterioration of cardiac symptoms was assessed as poor, with a correct answer rate to the specific question of 15.5%.

**Preventing Complications** Of all participants, 41.4% correctly answered the question “What is infective endocarditis?”, but only 3.4% correctly identified its symptoms.

Moreover, only 29.3% knew that the disease does not occur only once in a lifetime, which is considered poor knowledge. The correct answer rate for each risk factor for infective endocarditis ranged from 16.4% to 65.5%, thus revealing a lack of adequate knowledge on the topic.

**Physical Activity** The correct answer rate for whether it is acceptable to participate in competitive sports that require daily training was 69.0%, and that for whether it is necessary to choose a physically demanding job was 79.3%.

**Sex and Heredity** For sexual activity and heredity, more participants chose the option “does not know”, and the correct answer rate revealed poor knowledge.

**Contraception and Pregnancy** The domain of contraception and pregnancy was only completed by female participants. Regarding appropriate contraceptive methods, condoms had the highest correct answer rate (75.0%). In comparison, pills and coils had a low correct answer rate (28.6% and 14.3%, respectively), and many respondents chose the option “does not know”.

### Known-Groups Validity

Spearman’s rank correlation was used to verify Hypothesis 1 regarding the positive correlation between age and the LKQCHD total score. The correlation coefficient was  $\rho=0.268$  ( $P=0.042$ ; **Figure A**).

Hypothesis 2 was tested using 1-way ANOVA to determine differences in LKQCHD total scores between disease severity groups. Mean ( $\pm$ SD) LKQCHD total scores according to disease severity were  $71.4\pm 7.5$  for mild disease,  $53.0\pm 14.0$  for moderate disease, and  $51.1\pm 15.9$  for severe disease ( $\eta^2=0.131$ ,  $P=0.021$ ), thereby confirming significant group differences (**Figure B**).

### Convergent Validity

The mean ( $\pm$ SD) total score for the Resilience Assessment Tool was  $40.66\pm 5.49$ , and that for the Factor 1 score (“I can understand my disease”) was  $15.33\pm 2.28$ .

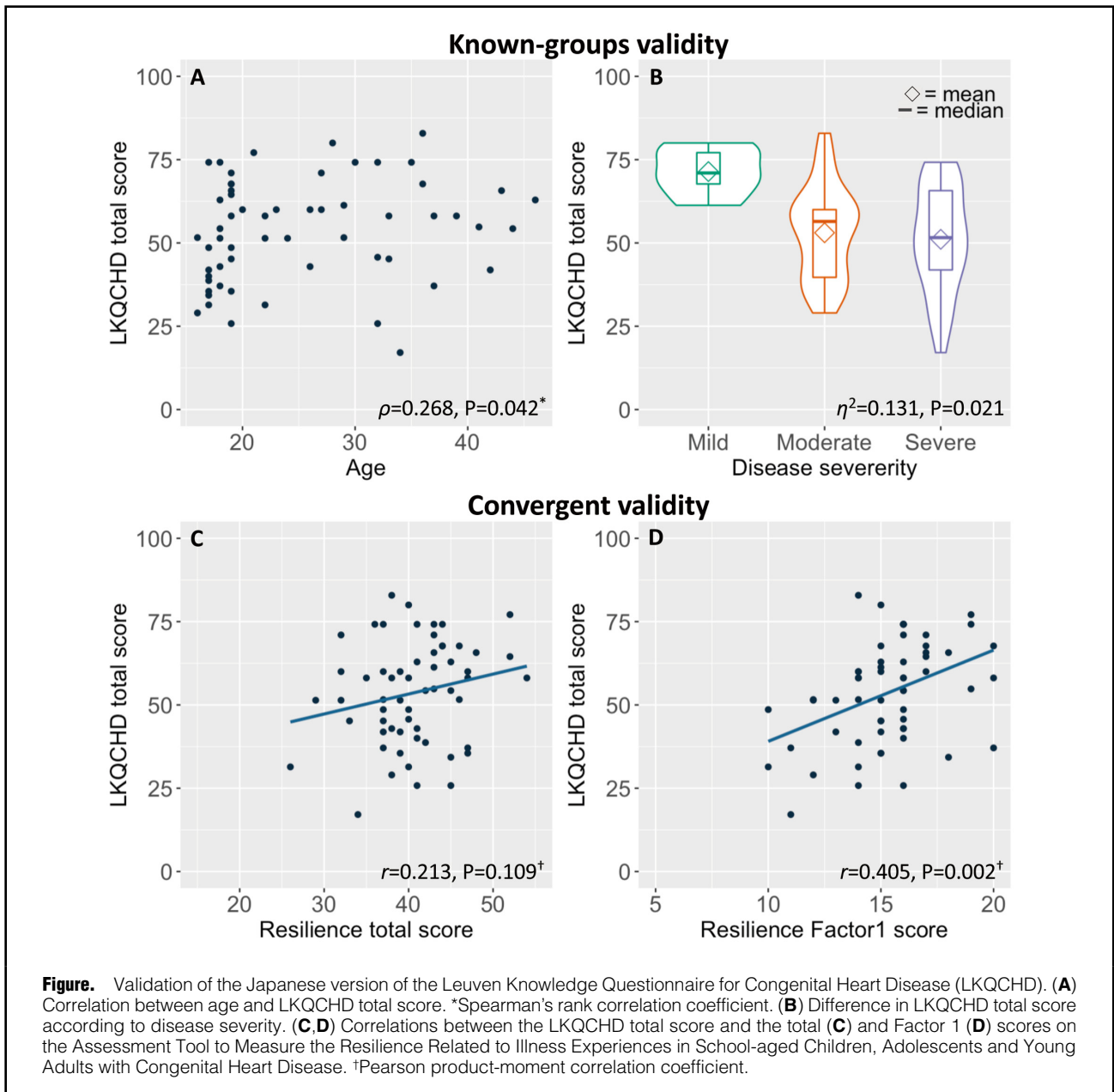
Hypothesis 3 predicted a positive correlation between total scores on the Resilience Assessment Tool and LKQCHD. The correlation coefficient was  $r=0.213$  ( $P=0.109$ ), confirming a positive but non-significant correlation (**Figure C**).

Hypothesis 4 posited a positive correlation between the Resilience Assessment Tool Factor 1 score and LKQCHD total score. The correlation coefficient was  $r=0.405$  ( $P=0.002$ ), which confirmed a significant positive correlation between the 2 (**Figure D**).

### Factors Associated With Disease Knowledge

**Table 4** presents factors affecting disease-related knowledge. The single regression analysis revealed that there were 5 variables with F-values of  $\geq 2$ : disease severity, educational level, accompanied or unaccompanied outpatient visits, people who communicate with doctors during outpatient visits, and experience of hearing the disease name from parents.

Multiple regression analysis showed that the LKQCHD total score was significantly associated with moderate ( $\beta=-0.46$ ,  $P=0.04$ ) and severe ( $\beta=-0.54$ ,  $P=0.02$ ) disease severity, compared with mild disease severity, and the experience of hearing the disease name from parents ( $\beta=0.25$ ,  $P=0.04$ ). Patients’ own communication with the doctor during the examination ( $\beta=0.24$ ,  $P=0.06$ ) and their education level ( $\beta=0.22$ ,  $P=0.09$ ) were not significant factors, but were positively associated with the LKQCHD total score.



### Discussion

This study's has 3 major findings. First, this study provides evidence of the validity of the Japanese version of the LKQCHD. Second, patients have inadequate knowledge about expected future complications, preventive strategies, heredity, pregnancy, and childbirth. Third, improving disease-related knowledge is affected by patients' independence and parental commitment. These 3 points are discussed below.

#### Validity of the Japanese Version of the LKQCHD

In this study, content validity and face validity were demonstrated during the development of the Japanese version of the LKQCHD, whereas the 4 hypotheses were confirmed during the survey process.

Known-groups validity was verified through Hypotheses 1 and 2. Hypothesis 1 confirmed that older age was associated with higher levels of disease-related knowledge, a result also reported for other diseases in studies of adolescents and young adults.<sup>15,30,31</sup> The correlation between age and disease-related knowledge among adolescents and young adults may be because disease awareness, understanding, and language skills are part of the growth process. Conversely, some studies have shown no correlation between age and disease-related knowledge for a broader population age,<sup>32</sup> and other studies have shown that disease-related knowledge is higher in younger age groups.<sup>33,34</sup>

In recent years, adolescents and young adults have grown up with explanations for the disease due to the upholding of the right of children to know and the need for transitional care. However, patients in older age groups may not



Table 4. Factors Related to the Total Score on the Leuven Knowledge Questionnaire for Congenital Heart Disease									
Variable (Reference)	Univariate regression analysis (n=58)				Multivariate regression analysis (n=57)				
	B	95% CI	$\beta$	P value	B	95% CI	$\beta$	P value	
Age	0.32	-0.15, 0.79	0.18	0.18	-	-	-	-	
Department (Pediatrics)									
Cardiology	5.65	-3.07, 14.37	0.17	0.20	-	-	-	-	
Disease severity (Mild)									
Moderate	-18.38	-32.80, -3.96	-0.59	0.01	-14.22	-27.94, -0.49	-0.46	0.04	
Severe	-20.34	-34.54, -6.14	-0.67	0.01	-16.69	-30.35, -3.03	-0.54	0.02	
Educational level (n=57; $\leq$ High school)									
>High school	8.13	0.09, 16.16	0.26	0.05	6.70	-1.06, 14.46	0.22	0.09	
Individuals accompanying patients (With parents)									
Alone or other	8.95	1.12, 16.77	0.29	0.03	1.96	-6.36, 10.28	0.06	0.64	
Individuals communicating with doctors during the outpatient examination (Parents)									
Himself/Herself	14.49	1.63, 27.36	0.29	0.03	11.96	-0.75, 24.67	0.24	0.06	
Parents have told me the name of the disease (No)									
Yes	13.45	-0.68, 27.58	0.25	0.06	13.58	0.52, 26.64	0.25	0.04	
My doctor has told me the name of the disease (No)									
Yes	7.52	-6.92, 21.96	0.14	0.30	-	-	-	-	

Multivariate regression model,  $R^2=0.313$ , adjusted  $R^2=0.231$ ,  $P=0.003$ .

have received explanations about their own diseases since they were children; therefore, it is necessary to continue to provide appropriate information to patients.

Hypothesis 2 was verified, indicating differences in disease-related knowledge depending on disease severity and that patients with mild disease have high disease-related knowledge. Previous studies have also shown that patients with less severe complex conditions have a better understanding of heart defects.<sup>13</sup> Patients with moderate or severe disease have undergone multiple surgeries, and their lesions have changed each time. Therefore, patients with mild disease easily answered questions about heart defects, which could explain why patients with mild disease had high disease-related knowledge.

Convergent validity was verified through Hypotheses 3 and 4. Hypothesis 3 was confirmed, revealing a positive correlation between the total scores on the Resilience Assessment Tool and the LKQCHD; however, the association was not significant. The reason for this could be that the Resilience Assessment Tool included components like psychological strength, support from others, and self-management in addition to disease-related knowledge. Furthermore, overseas programs to improve the resilience of patients with CHD include providing information about the disease<sup>35</sup> and the uncertainty of the disease related to the resilience of patients with chronic diseases;<sup>36</sup> therefore, disease-related knowledge may have some impact on resilience.

Hypothesis 4 was verified by a significant positive correlation between the Resilience Assessment Tool Factor 1 score and the LKQCHD total score. Factor 1, "I can understand my disease", measures the subjective assessment of disease knowledge, which is the same as disease knowledge measured by the LKQCHD. However, the effect size of  $r=0.405$  was not large, given that it measures knowledge about the same disease. The results of this study suggest

that subjective assessment alone is an insufficient measure of disease-related knowledge in patients with CHD.

#### Patients' Disease-Related Knowledge

Scores for the domains of the LKQCHD were  $>50$  for Disease and Treatment and Physical Activity. In contrast, scores for Preventing Complications, Sex and Heredity, and Contraception and Pregnancy were  $<50$ . Many patients knew the disease name, previous treatments, and restricted activities, but most were unaware of the expected future complications and prevention methods, heredity, and pregnancy and childbirth.

The poor level of knowledge about possible future complications was clear from the low correct answer rate for questions about symptoms of heart failure and infective endocarditis. Previous surveys in other countries have also shown a low rate of correct answers about symptoms.<sup>13-16</sup> Theories about self-care in heart failure include symptom recognition as part of the process of implementing self-care.<sup>37</sup> Even if a patient has never experienced the symptoms, not knowing the symptoms that may occur can delay medical consultation and possibly result in serious outcomes. Thus, patient education should include observation of symptoms, what can be done in case of deterioration, symptoms that the patient is currently aware of, and the clinical condition as seen by the healthcare provider.

Five patients with a history of loss to follow-up were included in the study. Previous studies have reported that patients with a history of loss to follow-up are older and more symptomatic.<sup>38</sup> In the present study, 72.4% of patients were aware of the need for lifelong cardiac care. Because patients lost to follow-up have a high rate of receiving invasive treatment,<sup>39,40</sup> it is necessary to explain the importance of lifelong cardiac care and education about the disease.<sup>27</sup>

One possible reason for the low correct answer rate for Sexuality and Heredity, as well as Contraception and Pregnancy, is the lag in sex education in Japan and the general avoidance of sex-related topics. For patients with CHD, pregnancy and childbirth cause significant hemodynamic changes, so patients need to know about contraception, family planning, and contraindications for pregnancy.<sup>41</sup> However, contraceptive counseling for patients with CHD is low, and counseling is not provided based on patient risk.<sup>42</sup> For patients with severe disease, both males and females require guidance regarding family planning because cardiovascular events such as death, surgery, and arrhythmia are linked to disease complexity<sup>43</sup> and economic status.<sup>44</sup> The fact that patients want to discuss family planning with their healthcare providers from an early stage<sup>45</sup> suggests the need to address this issue with disease-related knowledge.

### Factors Affecting Disease-Related Knowledge

The contextual factors explored in this study showed that patient independence and parental engagement affect patients' disease-related knowledge. Patient independence overlaps with transition readiness. Higher transition readiness is associated with higher levels of knowledge about the disease<sup>46</sup> and with making an outpatient visit alone.<sup>47</sup> In addition, most patients received information about the disease from their parents,<sup>48</sup> and because there is a correlation between the level of knowledge of patients and that of their parents,<sup>30</sup> it is important to encourage the parents.

### Clinical Implications

The Japanese version of the LKQCHD can be used in many ways, including with patients to identify gaps in knowledge or before and after a patient education intervention to verify the effectiveness of the intervention. However, the LKQCHD may be a burden for both the patient (because they may feel like they are being tested) and the healthcare provider (because they need to evaluate each patient based on their clinical condition). For this reason, it is necessary to remember that there may be differences between subjective and objective evaluations and to use the evaluations differently depending on the situation.

Disease-related knowledge has been found to be associated with health risk behaviors,<sup>49</sup> self-efficacy, and quality of life.<sup>50</sup> Knowledge of the disease is essential throughout a patient's life. Therefore, it is necessary for parents to communicate about diseases with children from an early age and to provide information about the problems faced in adulthood at an appropriate time.

### Study Limitations

The limitations of this study were relatively low number of participants included in this single-center study, and that only participants who could read and complete the questionnaire on their own were included. In the future, it will be necessary to expand the target population and consider support for patients with multiple disabilities, such as people with intellectual disability, who are unable to manage their disease on their own.

### Conclusions

We developed and validated the Japanese version of the LKQCHD and examined the factors that affect disease-

related knowledge. This study confirmed the validity of the Japanese version of the LKQCHD. There is a need to enhance patient education on long-term complications, prevention methods, heredity, pregnancy, and childbirth. In addition, patient independence and parental engagement have been suggested as effective in improving disease-related knowledge.

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### Disclosures

The authors declare no conflicts of interest.

### IRB Information

This study was approved by the Ethics Committee for Medical Research Involving Human Subjects of Yokohama City University (Reference no. B200400012).

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