Preferences Regarding Transfer of Patients With Congenital Heart Disease Who Attend Children’s Hospital

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Background: The aim of this study was to determine preferences regarding transfer of patients with congenital heart disease (CHD) attending a children's hospital in Japan and related factors.

Methods and Results: We conducted a self-administered questionnaire survey with CHD patients >15 years of age treated at the pediatric cardiology outpatient clinic of a children's hospital. Logistic regression analysis was used to identify factors related to patient preferences regarding the transfer. One hundred and eleven of the 122 patients given a questionnaire provided valid responses (valid response rate, 91.0%). Sixty-six subjects (64.9%) reported “not being told anything specific” by their physicians about the transfer from the children's hospital, and 72 (59.5%) stated that they “wished to continue attending the children's hospital”. Visiting outpatient clinic with parents (OR, 11.00; 95% CI: 2.01–60.97), having low uncertainty about continuing to attend the children's hospital (OR, 0.95; 95% CI: 0.92–0.98), and having high uncertainty about leaving the current physician (OR, 1.04; 95% CI: 1.01–1.07) were significantly related to the patient's wish to continue to attend the children's hospital.

Conclusions: There is a need to improve patient education regarding the opportunities for transfer, and to develop a systematic transition program for children's hospitals and aligned specialized adult CHD centers.

Key Words: Congenital heart disease; Health-care delivery; Patient preference; Pediatric hospital; Transition to adult care

Advances in medical treatment, cardiac surgery, and other invasive and non-invasive medical care over the last several decades have led to enormous growth in the number of adults with congenital heart disease (CHD) throughout the world. In Japan, as of 2011, it was estimated that there were at least 400,000 adult CHD (ACHD) patients; this number was expected to increase by approximately 9,000 patients annually. Consequently, the number of ACHD patients in Japan in 2018 approaches 500,000. Many ACHD patients have resida and sequelae, and therefore need lifelong medical care including surgery and catheter intervention. They also experience unique issues in adulthood, such as lifestyle disease, pregnancy, childbirth, and mental health issues. Accordingly, they need multidisciplinary medical care.

A specialized ACHD center, also called a regional ACHD center or a specialist center, is expected to play a central role in coordination of the ACHD care delivery system. The guidelines in Europe and North America call for 1 specialized ACHD center per 3–10 million people. Specialized ACHD centers are large, multidisciplinary centers with ACHD cardiologists, adult cardiologists, pediatric cardiologists, cardiac surgeons, and other related health-care providers with a wealth of experience of ACHD care and who are capable of meeting all potential needs of ACHD patients over their lifetime. A Canadian survey in 2014 indicated that the referral rate of patients to specialized ACHD centers increased after these guidelines were published and that specialized ACHD care was significantly related to reduced mortality.

In Japan, the number of specialized ACHD centers has been rapidly increasing over the past decade. In Europe and North America, specialized ACHD centers were established under the direction of ACHD cardiologists with an adult cardiology background from the 1950s onwards. In contrast, most Japanese CHD patients continue to receive follow-up by their pediatrician even after entering adulthood. For this reason, establishment of multidisciplinary approach-based specialized ACHD centers in Japan has
remained behind.\textsuperscript{7–10} Since the 1990s, pioneering specialized ACHD centers have been established independently of government support, especially high-volume centers in neighboring large cities such as Tokyo and Osaka. The establishment of the Japanese Network of Cardiovascular Departments for Adult Congenital Heart Disease (JNCVD-ACHD) in 2011 accelerated adult cardiologist participation in ACHD care and the establishment of specialized ACHD centers.\textsuperscript{11} A survey in 2014 found that there were 9 specialized ACHD centers throughout the nation, in contrast with the ideal number of 13–42 centers based on the guidelines\textsuperscript{3,4} and the Japanese population of 127 million people.\textsuperscript{10} Considering that JNCVD-ACHD has increased the number of its member facilities from 8 in 2011 to 38 in 2018,\textsuperscript{12} the number of specialized ACHD centers in Japan is expected to increase further.

The issue of transfer from pediatric health care to the adult health-care system follows the establishment of specialized ACHD centers in Japan. In Canada, only 47\% of patients >18 years of age receive treatment at one of the country’s 15 specialized ACHD centers.\textsuperscript{13} Given that the patients who are lost to follow-up are 3-fold more likely to receive urgent cardiac intervention, including surgical and catheter-based intervention, than patients who are effectively followed up,\textsuperscript{14} adequate transfer of such patients is an important problem in medical care. Also, given that in Japan those particular patients have been historically treated mainly by pediatricians, the possibility of patient and family member reluctance to be transferred to a specialized ACHD center may be high.

The issue of transfer is particularly compelling for patients attending children’s hospitals in Japan.\textsuperscript{8} CHD patients attending a pediatrics department of a general hospital may be able to continue receiving follow-up at the same institution even after entering adulthood if their cardiologist at the institution helps them do so. A total of 17 of the 29 member children’s hospitals of the Japanese Association of Children’s Hospitals and Related Institutions, however, were independent hospitals, often lacking sufficient personnel and facilities to take care of adult patients.\textsuperscript{10} Therefore, when wishing to be transferred to an adult care facility, patients attending such hospitals face the challenges of changing hospital and physician.

It is highly important in the transfer of a patient to respect the preferences of the patient and his/her family members, that is, patient first, in addition to considering the medical care necessary.\textsuperscript{15,16} In Europe, where specialized ACHD centers are established, ACHD patients consider switching to the ACHD program when they reach 16 years old.\textsuperscript{14} No research, however, has been performed to date with regard to the preferences of Japanese CHD patients about transfer from a children’s hospital to a specialized ACHD center. The aim of this study was therefore to conduct a survey to determine the preferences of CHD patients >15 years of age attending a children’s hospital with regard to transfer and the factors related to their preferences. Clarifying the patient’s wish will enable the most appropriate measures to be taken for their transfer. This study will also help to prevent patients being lost to follow-up.

**Methods**

**Participants**

CHD patients attending the pediatric cardiology outpatient clinic of a children’s hospital in the Kanto region of Japan were included in the survey. The outpatient clinic was operated by 3 board-certified pediatric cardiologists. The inclusion criteria were as follows: (1) age ≥15 years; (2) ability to complete a self-administered questionnaire; and (3) agreement to participate in the survey.

**Survey**

The survey consisted of a self-administered questionnaire and a medical record review. The survey was conducted from November 2009 through March 2010.

**Procedure**

The survey administrator used a survey prospectus to inform patients who met the eligibility criteria about the survey content when they visited the outpatient clinic, and then obtained written consent to participate in the survey. The patients who were able to complete the questionnaire at the visit, returned it upon completion. The patients unable to complete the questionnaire on site were asked to complete it at home and send it back by post.

| Table 1. Patient Characteristics (n=111) | Means±SD or n (%) |
|----------------------------------------|------------------|
| Age (years)                            | 25.7±6.9         |
| Gender                                 |                  |
| Male                                   | 59 (53.2)        |
| Female                                 | 52 (46.8)        |
| Cyanotic heart disease                 |                  |
| Yes                                    | 27 (24.3)        |
| No                                     | 84 (75.7)        |
| Hypoxemia                              |                  |
| Yes                                    |                   |
| No                                     |                   |
| NYHA class                             |                  |
| I                                       | 86 (77.5)        |
| II                                      | 18 (16.2)        |
| III                                     | 7 (6.3)          |
| Necessity for follow-up                |                  |
| Low                                     | 11 (9.9)         |
| Moderate                                | 47 (42.3)        |
| High                                    | 53 (47.7)        |
| Frequency of hospital visit            |                  |
| At least once per 3 months             | 77 (69.4)        |
| Less than once per 3 months            | 34 (30.6)        |
| Period attending the current physician | 1.9±1.4          |
| (years; n=105)                         |                  |
| Travel time to the children’s hospital | 72.4±43.9        |
| Visiting outpatient clinic             |                  |
| With a parent                          | 58 (52.3)        |
| Alone                                   | 53 (47.7)        |
| Living status                          |                  |
| With others                            | 97 (87.4)        |
| Alone                                   | 14 (12.6)        |
| Marital status                         |                  |
| Married                                 | 18 (16.2)        |
| Single                                  | 93 (83.8)        |
| Employment status                      |                  |
| Full-time                               | 41 (36.9)        |
| Other                                   | 70 (63.1)        |

NYHA, New York Heart Association.
Akaike’s information criterion (AIC), and consistent AIC were calculated. For calculation of the subscale scores, the sum of the scores for each item of the subscale was given between 0 and 100.

In a search for related factors, the participants were divided into 2 groups according to transfer preference (“those who wished to continue attending the children’s hospital” and “others”). A univariate analysis was performed on patient characteristics, clinical characteristics, and uncertainty and concern about the transfer from a children’s hospital. Categorical variables were tested using a chi-squared test or Fisher’s exact test, and continuous or ordinal variables were analyzed using a t-test. After confirmation of lack of multicollinearity among the variables, multiple logistic regression analysis was conducted with the transfer preferences as the dependent variables and related factors as the independent variables. Age, gender, and NYHA class were mandatorily entered, the variables with P<0.20 on univariate analysis were entered, and then variables were selected using the variable reduction method (likelihood ratio, P<0.15).

All statistical testing was 2-sided and had a level of significance of 5%. Statistical analysis was performed with SPSS Statistics version 24.0 and SPSS Amos version 24.0 for Windows.

**Ethics**

The study protocol was evaluated and approved by the Institutional Review Board (No. 380) and was performed in accordance with ethical standards, as described in the 2002 Declaration of Helsinki. Researchers gave the patients both oral and written explanation that no personally identifiable information including their response on preference

| Table 2. Patient Transfer Preferences (n=111) |
|-----------------------------------------------|
| **Transfer preference**                       |
| Wish to continue attending the children’s hospital | 66 | 59.5 |
| Wish to be transferred if a specialized center is available | 25 | 22.5 |
| No preference | 20 | 18.0 |
| **When would your transfer be appropriate?** |
| When my physician decides | 69 | 62.2 |
| When I start working | 13 | 11.7 |
| At the age of 20 | 19 | 17.1 |
| At the age of 18 | 5 | 4.5 |
| At the age of 15 | 4 | 3.6 |
| No answer | 1 | 0.9 |
| **How should your transfer take place?** |
| After attending a transition clinic | 73 | 65.8 |
| Without attending a transition clinic | 27 | 24.3 |
| After attending both physicians upon receiving a referral | 10 | 9.0 |
| Others | 1 | 0.9 |
| **Acceptable travel time to a new hospital (h)** |
| <0.5 | 12 | 10.8 |
| <1 | 53 | 47.7 |
| <1.5 | 20 | 18.0 |
| <2 | 12 | 10.8 |
| <3 | 2 | 1.8 |
| Duration is not an issue | 11 | 9.9 |
| No answer | 1 | 0.9 |

**Items**

The self-administered questionnaire asked the patients what their physician had told them about the transfer from a children’s hospital, their preference about the transfer from a children’s hospital, what uncertainty and concerns they had about the transfer, and desired procedures in the case of transfer. The items regarding their uncertainty and concerns about the transfer from a children’s hospital were extracted from the data of the previous qualitative research on health service needs from 17 Japanese ACHD patients. The response to each item was scored on a 5-point Likert scale. The questionnaire also asked the patients their gender, age, living and marital status, and other patient characteristics.

Patient medical records were reviewed to determine disease type (cyanotic or not), surgical history, presence of hypoxemia, New York Heart Association (NYHA) functional classification, and other clinical characteristics.

**Statistical Analysis**

Descriptive statistics were calculated for the patient characteristics, the physician-provided information about the transfer from a children’s hospital, preferences about the transfer from a children’s hospital, uncertainty and concerns about the transfer from a children’s hospital, and desired procedures in the case of transfer.

Exploratory factor analysis using promax rotation was conducted to summarize the items on uncertainty and concerns about the transfer from a children’s hospital. We also used confirmatory factor analysis to confirm the fit of the models to the data. The ratio of chi-squared to the degrees of freedom, the goodness-of-fit index (GFI), the adjusted GFI (AGFI), the comparative fit index (CFI), the root mean square error of approximation (RMSEA),
regarding the transfer would be disclosed even to their attending physician throughout the research process, and that it would never affect future medical care. Patients were included in the study only if they provided written informed consent.

## Results

### Patient Characteristics
One hundred and eleven of the 122 patients given the questionnaire provided valid responses (valid response rate, 91.0%). Mean participant age was 25.7±6.9 years; 59 participants (53.2%) were male; 86 (77.5%) were NYHA class I; 38 (16.2%) were NYHA class II; and 7 (6.3%) were NYHA class III (Table 1). Seventy-six (68.5%) had cyanotic heart disease, and 77 (69.4%) visited the hospital at least once every 3 months.

### Patient Preferences Regarding Transfer
Regarding transfer preferences, 66 participants (59.5%) answered that they “wished to continue attending the children’s hospital”; 25 (22.5%) responded that they “wished to be transferred if a specialized center is available”; and 20 (18.0%) answered “no preference” (Table 2). When asked about the timing of the transfer, 69 participants (62.2%) answered that “when my physician decided, the transfer should be appropriate” regardless of age. When asked how the transfer should take place if they were to be transferred, 73 participants (65.8%) responded “after attending a clinic to be transferred to”.

### Information Provided About the Transfer
Seventy-two participants (64.9%) stated that they “were not told anything specific” by their physician about the transfer from the children’s hospital. Seventy-four (66.7%) stated that they were “very” or “somewhat” interested in getting information about the transfer. The most desired information source was their physician for 108 participants (97.3%; Table 3).

### Uncertainty and Concerns About the Transfer
More than three-fourths of the participants answered that it was “very” or “somewhat” true that they were “unexplainably uncertain about changing physicians”, “uncertain if a new physician would understand my specific disease status”, “unsure about what institution could

### Table 3. Information Provided About the Transfer (n=111)

| Question                                                                 | n  | %   |
|--------------------------------------------------------------------------|----|-----|
| What did your physician tell you about your transfer?                    |    |     |
| To continue attending the children’s hospital                            | 25 | 22.5|
| Better to be transferred to a specialized institution upon reaching adulthood | 14 | 12.6|
| Not told anything specific                                                | 72 | 64.9|
| Where do you get information about transfer? (multiple answers allowed)   |    |     |
| Have received no specific information                                     | 63 | 56.8|
| My physician                                                              | 28 | 25.2|
| Specialist other than my physician                                       | 7  | 6.3 |
| Non-physician health-care professional                                    | 5  | 4.5 |
| Family member                                                             | 5  | 4.5 |
| Friend or acquaintance                                                    | 6  | 5.4 |
| Television/radio                                                          | 3  | 2.7 |
| Newspaper/magazine                                                        | 2  | 1.8 |
| Internet                                                                  | 8  | 7.2 |
| Patient group                                                             | 3  | 2.7 |
| Other                                                                     | 2  | 1.8 |
| Do you want information about transfer?                                   |    |     |
| Very much                                                                | 40 | 36.0|
| Somewhat                                                                 | 34 | 30.6|
| Indifferent                                                               | 22 | 19.8|
| Not very much                                                             | 11 | 9.9 |
| Not at all                                                                | 4  | 3.6 |
| From whom do you want to get information about transfer? (multiple answers allowed) |    |     |
| My physician                                                              | 108| 97.3|
| Specialist other than my physician                                       | 31 | 27.9|
| Non-physician health-care professional                                    | 14 | 12.6|
| Family member                                                             | 5  | 4.5 |
| Friend or acquaintance                                                    | 6  | 5.4 |
| Television/radio                                                          | 12 | 10.8|
| Newspaper/magazine                                                        | 7  | 6.3 |
| Internet                                                                  | 19 | 17.1|
| Patient group                                                             | 7  | 6.3 |
| Other                                                                     | 2  | 1.8 |
Factors Related to Transfer Preferences

On logistic regression analysis the following factors were significantly related to the preference of continuing to attend the children's hospital (Table 5): visiting outpatient clinic with parents (OR, 11.00; 95% CI: 2.01–60.97), having low uncertainty about continuing to attend the children's hospital (OR, 0.95; 95% CI: 0.92–0.98), and having high uncertainty about leaving the current physician (OR, 1.04; provide specialized care”, or “concerned that treatment policy might change if I should change physicians” (Table 4). On factor analysis the following 5 factors consisting of 13 items were extracted: “uncertain about a new physician”, “uncertain about continuing to attend the children's hospital”, “uncertain about changing physicians”, “uncertain about changing hospitals”, and “uncertain about leaving the current physician”. Cronbach’s α coefficient was 0.88–0.70 for each domain. The cumulative contribution rate was 66.1%. On confirmatory factor analysis with maximum likelihood estimation the GFI was 0.887, AGFI was 0.796, CFI was 0.927, RMSEA was 0.088, AIC was 170.837, CAIC was 302.380.

### Table 4. Factor Analysis for Uncertainty and Concerns About Transfer (n=106)

| Factor | Load |
|--------|------|
| Uncertain about new physician | 0.88, 0.87, 0.83, 0.67 |
| Uncertain about changing physicians | 0.94, 0.77 |
| Uncertain about continuing to attend children's hospital | 0.81, 0.71, 0.54 |
| Uncertain about leaving current physician | 1.06, 0.62 |
| Factor correlation | 0.51, −0.22, −0.09, −0.12, 0.54, 0.68, −0.49, 0.40 |

$\chi^2 = 98.837$ (df=55, $P<0.001$), GFI=0.887, AGFI=0.796, CFI=0.927, RMSEA=0.088, AIC=170.837, CAIC=302.380.

### Table 5. Multivariate Indicators of Patient Preference to Continue Attending Children's Hospital (n=101)

| Variable | OR | 95% CI | P-value |
|----------|----|--------|---------|
| Age      | 1.05 | 0.94–1.17 | 0.73 |
| Gender: Male/(Female) | 0.77 | 0.22–2.73 | 0.39 |
| Necessity for follow-up: Moderate/(Low) | 2.22 | 0.26–18.91 | 0.43 |
| Necessity for follow-up: High/(Low) | 8.25 | 0.75–90.48 | 0.06 |
| Travel time to the children's hospital | 0.99 | 0.97–1.00 | 0.15 |
| Visiting outpatient clinic with a parent/(alone) | 11.00 | 2.01–60.97 | 0.01 |
| Factor 1: Uncertain about new physician | 1.03 | 0.97–1.06 | 0.09 |
| Factor 3: Uncertain about continuing to attend children's hospital | 0.95 | 0.92–0.98 | 0.00 |
| Factor 5: Uncertain about leaving current physician | 1.04 | 1.01–1.07 | 0.02 |

OR, odds ratio; CI, confidence interval. Input variables: Age, Gender, Necessity for follow-up, Frequency of hospital visit, Travel time to the children hospital, Visiting outpatient clinic with a parent, Living status, Physician’s explanation about transfer, Period for attending the current physician, Factor 1: Uncertain about new physician, Factor 2: Uncertain about changing physicians, Factor 3: Uncertain about continuing to attend children’s hospital, Factor 4: Uncertain about changing hospitals, Factor 5: Uncertain about leaving current physician. Reference categories stated in parentheses. Hosmer-Lemeshow test of goodness of fit, $P=0.002$. Negerlerke $R^2=0.586$. 

OCHIAI R et al.
Discussion
To the best of our knowledge, the present study is the first to elucidate, in a quantitative manner, the preferences of CHD patients concerning transfer from a children's hospital to a specialized medical institution for adults, and the factors related to their preferences. The most important findings of the present study are the following. First, approximately 60% of patients wish to continue to attend the children's hospital even after reaching adulthood. Second, approximately 65% of patients have not received explanation concerning the transfer from their physician. Third, the possibility is suggested that acquiring self-management ability such as visiting the outpatient clinic alone promotes the transfer. These 3 points are elaborated as follows.

Wish to Continue to Receive Ongoing Care at the Children's Hospital
In this study, around 60% of the participants stated a preference for ongoing care at their children's hospital. The nationwide survey that was conducted around the same time as the present study found that the number of facilities with the potential to become specialized ACHD centers was 14 in Japan, and that the reason for this small number was a lack of interest/concern by cardiologists. Given that the medical care system in this field is not well developed, many patients may not wish to be transferred to specialized ACHD centers. This indicates a different situation in Japan compared with Europe, where the transfer of patients to specialized ACHD centers is considered normal. After the present survey was conducted, participation of cardiologists in the field of ACHD has been promoted. It is thus expected that patient preference concerning the transfer could change, also in Japan, with further establishment of appropriate medical care systems in the future. Additionally, in 2017, the Japanese Ministry of Health, Labor and Welfare sent a notification to each of 47 prefectures in Japan to establish at least 1 transition support center in every prefecture and to coordinate regional health-care resources such as pediatricians, adult physicians, nurses, social workers, teachers, and patient groups for smooth transitions. Transition support centers treat not only patients with CHD but all patients with childhood-onset chronic disease. Establishment of a community-based transition support system may also change patient preference regarding their transfer.

The fact that many children's hospitals are independent of adult care centers, a peculiar situation in Japan, may also have affected participant transfer preference. In the present study, “having low uncertainty about continuing to attend the children’s hospital” and “having high uncertainty about leaving the current physician” were important factors regarding the patients’ wish to continue attending their children’s hospital. Those patients attending the pediatrics department of a specialized ACHD center do not have to be transferred to another facility, given that they are able to continue to see their attending physician. In contrast, transfers from independent children’s hospitals consequently entail those to other facilities and involve change of the attending physician. Because of this, the patients attending the independent children’s hospital may have had more uncertainty and concern about leaving their current physicians, and therefore, many patients preferred to continue ongoing care at their children's hospital.

A total of 66% of the participants stated that the transfer, when performed, should take place “after a transfer visit.” Some medical institutions in Western countries offer transfer visits at which the adult care physician and pediatrician attend at the same time. A few institutions in Japan have recently started to offer the opportunity for a patient to see both a cardiologist at the university hospital to which the patient will be transferred, and the pediatric cardiologist at the independent children's hospital, not necessarily on the same occasion, to help the patient get used to a new environment. Calls for a similar kind of transfer visit have also been heard in qualitative research conducted in Japan on patients and families. Providing sufficient time for a patient to go back and forth between their independent children's hospital and a specialized ACHD center for a gradual transfer may reduce the patient psychological burden. Also, the possibility has been proposed of a children's hospital merging with a general hospital, which should also reduce psychological burden and geographic hurdles involved in the transfer from the children’s hospital. These proposals must be seriously considered in the future.

Lack of Explanation About the Transfer by the Physician
A total of 65% of the participants stated that they had not been told anything specific about the transfer by their physician. With the lack of an established network of specialized ACHD centers at the time of the current study, physicians in Japan therefore could not recommend a transfer. Nonetheless, 67% of the participants wanted information about the transfer, and 93% of them wanted to get this information from their physician. According to a study in Canada, patients whose physicians described the necessity of the transfer in the medical record were transferred to a specialized ACHD center in an appropriate manner. In addition, in recent randomized controlled trials (RCT) on the transitional care for CHD patients, explanations about the necessity of transfer or continued medical care were incorporated as part of the intervention program, and such interventions were shown to reduce the delay in visiting a specialized ACHD center. It is considered that the transfer to a specialized ACHD center will be promoted and that prevention of loss to follow-up will become more important than ever. Pediatric cardiologists in particular should inform patients about the necessity for lifelong follow-up and the possibilities of transfer in the future.

Patient Self-Management and Promotion of Transfer
Participants who were accompanied by their parent when they visited the hospital preferred to continue visiting their current children's hospital. A previous Canadian study showed that patients visiting the outpatient clinic alone were more likely to consistently seek care at a specialized center. Although disease severity and geographical constraints sometimes necessitate the presence of the parent during the patient’s visit to the hospital and during consultation in Japan, it is important to take measures to promote patient self-management, such as the patient’s visiting clinics alone upon reaching puberty or, even when visiting the clinic with a parent, acting as the primary communicator with the physician. In a US RCT, after tw 1-h nurse-led educational sessions, more patients in the intervention group answered the majority of physicians’
questions by themselves than in the control group, whereas the proportion of patients attending clinic alone did not differ between the groups.\textsuperscript{18} Nurses in Japan should also play more significant roles in transitional care, and systematic programs should be established to educate patients in self-management skills and to facilitate a smooth transfer to an adult health-care system. In addition, the recent Canadian study reported that the self-management scores for transition readiness in CHD patients aged 12–15 years were higher when parents had discussed the transfer with their child, and when parents had discussed the transfer with a health-care provider.\textsuperscript{19} Therefore, it is considered that future transition programs should incorporate parents’ involvement.

Limitations and Issues
The present survey should be expanded to involve more patients, to make the results more generalizable, given that it was conducted at 1 independent children’s hospital in the Kanto region. Physician-patient discussions about the transfer from a children’s hospital and patient preferences for the transfer are expected to vary depending on medical institution and region. Further study should be conducted with more institutions to help build medical care systems that take regional characteristics into consideration.

Conclusions
There is a need to improve the education of patients regarding the opportunities of transfer, and to develop systematic transition programs for children’s hospitals and their aligned specialized ACHD centers.

Acknowledgments
The authors of this manuscript express their heartfelt gratitude to all participants.

Name of Grant
This research was supported by a grant-in-aid, Japanese Ministry of Health, Labour and Welfare (20111001B).

Disclosures
The authors declare no conflicts of interest.

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