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ORIGINAL ARTICLE
Pediatric Cardiology and Adult Congenital Heart Disease

Nationwide Survey on Transitional Care for Patients With Childhood-Onset Cardiomyopathy in Japan

Katsura Soma, MD, PhD; Ryota Ochiai, PhD; Hiroyuki Tsutsui, MD, PhD, FJCS; Norihiko Takeda, MD, PhD; Atsushi Yao, MD, PhD

Background: Individuals transitioning into adulthood require age-appropriate medical care and delegation of decision-making authority from their parents to the patients themselves. Although there have been multiple observational and interventional studies on transitional care for patients with congenital heart disease (CHD) in the cardiovascular field, transitional care specific to childhood-onset cardiomyopathy (CM) remains unaddressed.

Methods and Results: A nationwide questionnaire-based survey was performed in the pediatric cardiology departments of 151 facilities in Japan. Responses were obtained from 100 (66%) facilities with low transfer rates (<5%) for childhood-onset CM cases. The comparison between CHD-transferring and non-CHD-transferring facilities revealed a significantly higher transfer rate (83.9%) for childhood-onset CM cases in the CHD-transferring facilities (P<0.001). Regarding the transition programs, 72 (72%) facilities do not offer any programs for CM, while most (92%) facilities recognize its necessity. Finally, only 19 (19%) facilities provided a transition program, 10 of which were CHD based.

Conclusions: To the best of our knowledge, this is the first study to demonstrate the poor transition/transfer care status of patients with childhood-onset CM in Japan. The transfer rate of CMs was lower than that of CHDs, and transition programs were less available. Referring to the system established for CHD could help develop a successful transitional care system for CM.

Key Words: Childhood-onset cardiomyopathy; Congenital heart disease; Transfer; Transitional care

Transitioning into adulthood encompasses not only the ability to receive age-appropriate medical care considering complications and long-term outcomes (referred to as transfer) but also the delegation of decision-making authority from parents to the patients themselves.[1–4] Despite recognizing the necessity of transitional care for various chronic pediatric conditions, in routine clinical practice, patients are often merely transferred to different departments without adequate support to achieve self-sufficiency.[5,6] Moreover, there are instances in which patients with childhood-onset chronic diseases continue to visit pediatric departments without being transferred to specialized adult care facilities.[7]

For patients with childhood-onset chronic diseases, transitional care is of immense importance to ensure lifelong medical care. In Europe, North America, and Japan, the transition in the field of adult congenital heart disease (ACHD) has received early attention, and specialized ACHD centers have been founded, making it possible for patients with ACHD to be transferred to these centers.[8–12] In Japan, the Japanese Network of Cardiovascular Departments for Adult Congenital Heart Disease (JNCVD-ACHD) was established in 2011. Presently, it provides specialized outpatient clinics throughout the country (https://www.jncvd-achd.jp/facilities/). As part of the JNCVD-ACHD, a registry study has been ongoing since 2013 aimed at comprehensively understanding the status of transition and transfer among patients with congenital heart disease (CHD).[12] Based on JNCVD-ACHD participating facilities, a board-certified specialist system of the Japanese Society for Adult Congenital Heart Disease was approved in 2019. Multiple studies using big data suggest that referring patients to ACHD-specialized centers may improve their prognosis.[13,14] Additionally, several interventional studies have shown that transition programs improve patients' readiness and encourage appropriate

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Department of Cardiovascular Medicine, Graduate School of Medicine, The University of Tokyo, Tokyo (K.S., N.T.); Adult Nursing, Department of Nursing, School of Medicine, Yokohama City University, Yokohama (R.O.); Department of Cardiovascular Medicine, Division of Cardiovascular Medicine, Research Institute of Angiocardiology, Faculty of Medical Sciences, Kyushu University, Fukuoka (H.T.); International University of Health and Welfare, Tokyo (H.T.); and Division for Health Service Promotion, The University of Tokyo, Tokyo (A.Y.), Japan

Mailing address: Ryota Ochiai, PhD, Adult Nursing, Department of Nursing, School of Medicine, Yokohama City University, 3-9 Fukuura, Kanazawa-ku, Yokohama, Kanagawa 236-0004, Japan. email: rochiai@yokohama-cu.ac.jp

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Table 1. Background of Participating Facilities and Respondents

	All (n=100)		Facility type					
			University hospital (n=44)		General hospital (n=43)		Children's hospital (n=13)	
	n	%	n	%	n	%	n	%
Region								
Hokkaido	4	4.0	3	6.8	0	0.0	1	7.7
Tohoku	5	5.0	4	9.1	1	2.3	0	0.0
Kanto	32	32.0	13	29.5	12	27.9	7	53.8
Chubu	21	21.0	7	15.9	12	27.9	2	15.4
Kinki	9	9.0	4	9.1	3	7.0	2	15.4
Chugoku	9	9.0	4	9.1	5	11.6	0	0.0
Shikoku	3	3.0	2	4.5	1	2.3	0	0.0
Kyushu/Okinawa	17	17.0	6	13.6	10	23.3	1	7.7
JNCVD-ACHD participation								
Yes	32	32.0	26	59.1	6	14.0	0	0.0
No	68	68.0	17	38.6	38	88.4	13	100.0
Respondents' certification (multiple choice)								
Board-certified pediatrician	91	91.0	38	86.4	42	97.7	11	84.6
Board-certified pediatric cardiologist	94	94.0	42	95.5	41	95.3	11	84.6
Board-certified adult cardiologist	15	15.0	10	22.7	4	9.3	1	7.7
Board-certified ACHD cardiologist	32	32.0	17	38.6	9	20.9	6	46.2
Others	5	5.0	3	6.8	0	0.0	2	15.4

ACHD, adult congenital heart disease; JNCVD-ACHD, Japanese Network of Cardiovascular Departments for Adult Congenital Heart Disease.

referrals to ACHD-specialized centers.[15,16]

However, the status of transitional care for patients with childhood-onset cardiomyopathy (CM) without structural anomalies remains unknown. Despite the promotion of transitional care in other countries, studies focusing on CM-specific transitional care are lacking.[17] For instance, although meticulous documentation exists regarding the number of patients with CM during their initial pediatric visits, their subsequent transfer status remains unclear.[18] Therefore, this study was conducted to clarify the current status of transitional care for patients with CM and determine whether it is similar to that of patients with CHD. The novelty of this study is based on the fact that it evaluates the status of transitional care for patients with CM. The findings will indicate whether transitional care for patients with CM should proceed in the same manner as ACHD or if unique measures are needed.

Methods

Study Design

This was an observational, questionnaire-based nationwide survey of pediatric cardiology departments in Japan.

Participants

A total of 144 facilities registered as teaching hospitals/hospital groups for the board certification system of the Japanese Society of Pediatric Cardiology and 7 member facilities of the Japan Council of Pediatric Comprehensive Medical Facilities participated in this study. Paper-based questionnaires were sent to the directors of Pediatric Cardiology Departments in the 151 facilities. Directors were asked to complete the questionnaires themselves or delegate the responses to a physician dedicated to or interested in managing childhood-onset CM in their department.

Childhood-Onset CMs Targeted in the Study

We examined childhood-onset CMs with high prevalence based on the Japanese Society of Pediatric Cardiology's Rare Disease Surveillance Report for the period 2015–2020.[18] These include dilated CM (DCM), hypertrophic CM (HCM), restrictive CM (RCM), arrhythmogenic right ventricular CM (ARVC), left ventricular noncompaction (LVNC), and other CMs associated with systemic diseases (e.g., muscular dystrophy, mitochondrial CM, Fabry's disease).

Questionnaire Items

The following questions were asked to clarify the status of transitional care in CM:

(1) Basic information on participating facilities and participants.

(2) Number of patients with CM aged <20 years on their first visit to participating facilities in the past 5 years (from 2016 to 2020 fiscal years). Answer choices were "0", "1–4", "5–9", "10–19", "20–49", "50–99", and "100".

(3) The proportion of patients with CM who reached the age of 15 years and were transferred to an adult healthcare setting during the period mentioned above (hereafter referred to as transfer rate). Answer choices were "0%", "1–24%", "25–49%", "50–74%", "75–99%", "100%", and "No applicable patients".

(4) Transfer destinations by CM type. The answer choices were "cardiology department at own facility", "cardiology departments at other facilities", "ACHD department at own facilities", "ACHD departments in other facilities", "specialist facility for severe heart failure", "specialist facility for arrhythmias", "others", and "not transferred".

The following questions were asked to determine whether transitional care for patients with CM should be similar to

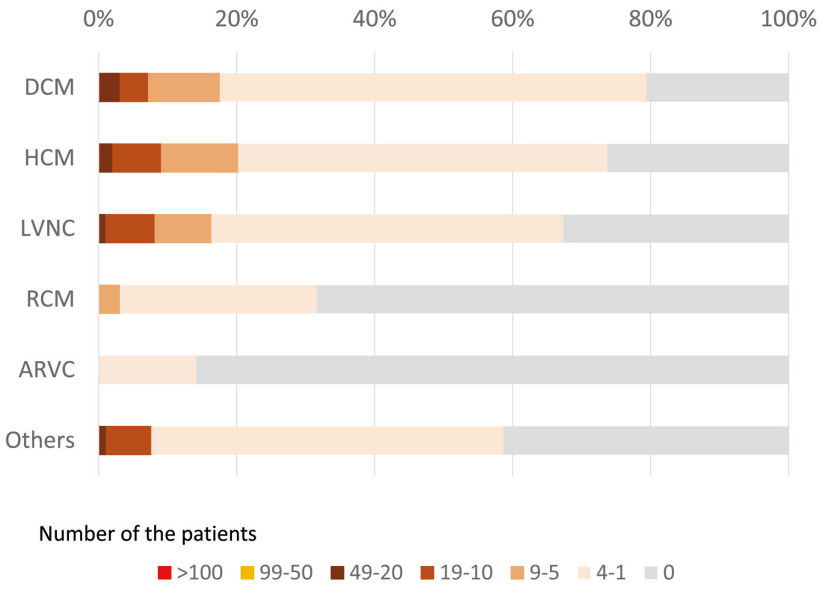

Figure 1. Number of new patients with childhood-onset cardiomyopathy (CM) aged <20 years at their first visit between 2016 and 2020. The same color bars ordered from left to right are the percentages of facilities that experienced ≥100, 99–50, 49–20, 19–10, 9–5, 4–1, and 0 new cases for each CM, respectively. Among all CMs, no facilities experienced ≥50 new cases, and most facilities reported fewer than 5 new cases. ARVC, arrhythmogenic right ventricular CM; DCM, dilated CM; HCM, hypertrophic CM; LVNC, left ventricular noncompaction; Others, other CMs associated with systemic diseases (e.g., muscular dystrophy, mitochondrial CM, Fabry disease); RCM, restrictive CM.

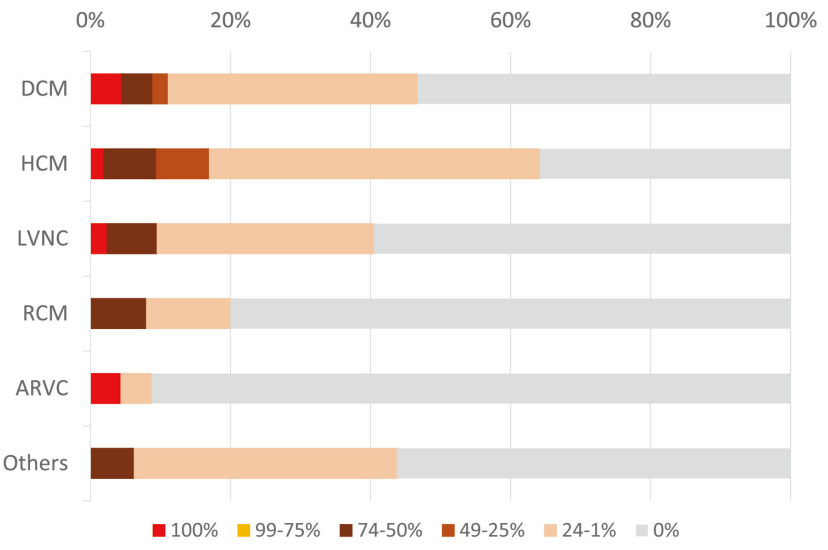

Figure 2. Transfer rate of patients with childhood-onset cardiomyopathy (CM) who reached age 15 years between 2016 and 2020. The percentages of facilities reporting 100%, 99–75%, 74–50%, 49–25%, 24–1%, and 0% as a transfer rate are shown as the same-colored bars ordered from left to right, respectively. Only a few facilities reported a 100% transfer rate, with 80–95% of facilities reporting a transfer rate of 1–24% or 0%. ARVC, arrhythmogenic right ventricular CM; DCM, dilated CM; HCM, hypertrophic CM; LVNC, left ventricular noncompaction; Others, other CMs associated with systemic diseases (e.g., muscular dystrophy, mitochondrial CM, Fabry disease); RCM, restrictive CM.

that for patients with CHD:

(5) Facility/department's policy for transferring patients with childhood-onset CM and CHD (hereafter, transfer policy). The answer choices were "transferring them to adult departments", "not transferring them to adult departments", and "others".
(6) Need and availability of transition programs for patients with childhood-onset CM and CHD.

Statistical Analysis

Descriptive statistics were conducted for each questionnaire item. Data were presented as mean±SD for normally distributed continuous variables. Ordinal and categorical data were presented as frequencies and percentages. Pearson's χ-square or Fisher's exact tests were used as appropriate to compare the number of CM cases, transfer rates, transfer destinations, and the need and availability of transition programs by facility types and partly by CM types. Spearman's correlation coefficient was calculated to determine the association between the number of CM cases and transfer rates. We also conducted a Fisher›s exact test to evaluate the relationship between transfer policies for patients with CM and CHD. All tests were two-tailed, and the significance level was set at $P<5\%$. Statistical analyses were performed using IBM SPSS version 29.

Ethical Considerations

This study was approved by the Ethics Committee of the Tokyo University Graduate School of Medicine and Faculty of Medicine (reference no. 2022377NI). Research procedures followed the Declaration of Helsinki. We explained to the participants via a letter of intent that participation

Table 2. Correlation Between the Number of CM Cases and Transfer Rate

	n	Spearman's ρ	P value
DCM	43	0.36	0.02
HCM	48	0.47	0.001
LVNC	39	0.43	0.01
RCM	13	0.72	0.01
ARVC	8	–	–
Others	41	0.26	0.09

Facilities with zero cases were excluded from the analysis. ARVC, arrhythmogenic right ventricular cardiomyopathy; CM, cardiomyopthy; DCM, dilated cardiomyopathy; HCM, hypertrophic cardiomyopathy; LVNC, left ventricular noncompaction; Others, other cardiomyopathies associated with systemic diseases (e.g., muscular dystrophy, mitochondrial cardiomyopathy, Fabry disease); RCM, restrictive cardiomyopathy.

was voluntary. They were assured that choosing not to participate would not result in any disadvantages. Furthermore, we emphasized our commitment to maintaining the confidentiality of personally identifiable information.

Results

Participants' Backgrounds

Of the 151 facilities invited to participate in this study, valid responses were obtained from 100 facilities (response rate of 66.2%), consisting of 43 university hospitals, 44 general hospitals, and 13 independent children's hospitals. Ninety-four responding physicians were board-certified pediatric cardiologists. Twenty-six (59.1%) of the university hospitals and 6 (14.0%) of the general hospitals were JNCVD-ACHD participating facilities (**Table 1**). Notably, JNCVD-ACHD participation was restricted to university and general hospitals; therefore, children's hospitals were not included in the JNCVD-ACHD participating facilities.

Number of Cases, Transfer Rates, and Transfer Destinations Among CM Cases

The number of CM cases in patients aged <20 years at their first visit to the participating facilities from 2016 to 2020 was mostly 1–4 for all CM types. In addition, 20–84% of facilities had never treated a single case across all types of CMs. Hence, 80–100% of the facilities encountered only a small number (0–4) of new patients aged <20 years with CM (**Figure 1**).

Regarding the transfer rates (**Figure 2**) of the cases reaching the age of 15 years during the same period, <5% of the facilities reported that they transferred all the relevant patients with any type of CM to adult healthcare settings. Facilities that indicated that they had no applicable patients were excluded from the following analysis. Across all types of CM, 31–91% of the facilities had never transferred a single case. Furthermore, children's hospitals exhibited a higher transfer rate (76.9%) than other facility types (**Supplementary Table 1**). Approximately 50% of university and general hospitals reported a 0% transfer rate

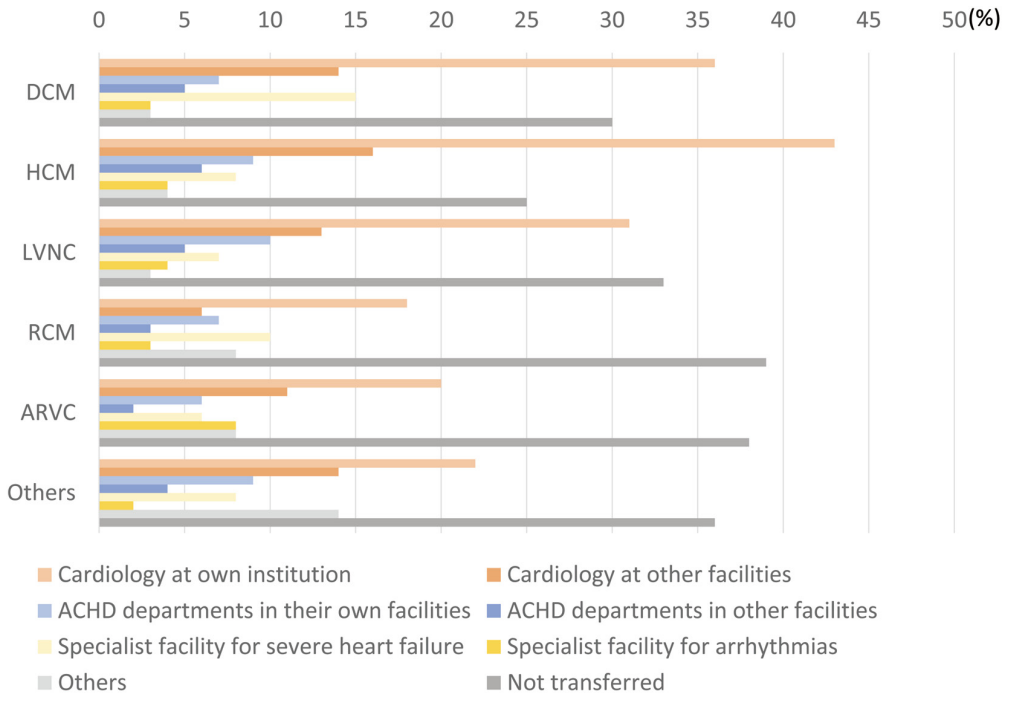

Figure 3. Difference in transfer destination for each cardiomyopathy (CM). Each color bar indicates a transfer destination, as shown below the figure, and the percentage in the graph for each CM. Among all CMs, the most popular transfer destination is cardiology at own institute, with approximately 20–40%. ACHD, adult congenital heart disease; ARVC, arrhythmogenic right ventricular CM; DCM, dilated CM; HCM, hypertrophic CM; LVNC, left ventricular noncompaction; Others, other CMs associated with systemic diseases (e.g., muscular dystrophy, mitochondrial CM, Fabry disease); RCM, restrictive CM.

Table 3. Relationship of Transfer Policies for CM and CHD

	Transfer of patients with CM to adult healthcare settings						
	Yes (n=62)		No (n=17)		Others (n=17)		P value
	n	%	n	%	n	%	
Transfer of patients with CHD to adult healthcare settings							
Yes	52	83.9	3	17.6	6	35.3	<0.001
No	2	3.2	14	82.4	3	17.6	
Others	8	12.9	0	0.0	8	47.1	

CHD, congenital heart disease; CM, cardiomyopthy.

Table 4. Need and Availability of Transition Programs for CM and CHD

	Need for transition program for CM								
	Necessary as much as CHD (n=55)		Not as much as CHD, but necessary (n=37)		Unnecessary (n=3)		Others (n=2)		P value
	n	%	n	%	n	%	n	%	
Availability of transition program									
Program for CHD is available for CM	9	16.4	1	2.7	0	0.0	0	0.0	0.253
Program for childhood onset disease is available for CM	4	7.3	5	13.5	0	0.0	0	0.0	
No program is available for CM	39	70.9	29	78.4	3	100.0	1	50.0	
Others	3	5.5	2	5.4	0	0.0	1	50.0	

"No program is available for CM" includes both with and without programs for CHD and childhood onset diseases. Percentage may not sum to 100% due to missing values. CHD, congenital heart disease; CM, cardiomyopthy.

Table 5. Transfer Policy and Transition Program by JNCVD-ACHD Participation

	JNCVD-ACHD participation				
	Yes (n=32)		No (n=68)		P value
	n	%	n	%	
Transferring patients with CHD to adult healthcare settings					
Yes	21	65.6	40	58.8	0.204
No	7	21.9	12	17.6	
Others	2	6.3	14	20.6	
Transferring patients with CM to adult healthcare settings					
Yes	21	65.6	41	60.3	0.680
No	5	15.6	13	19.1	
Others	4	12.5	13	19.1	
Need for transition program for CM					
Necessary as much as CHD	21	65.6	36	52.9	0.463
Not as much as CHD, but necessary	9	28.1	28	41.2	
Unnecessary	1	3.1	2	2.9	
Others	1	3.1	1	1.5	
Availability of transition program for CM					
Program for CHD is available for CM	5	15.6	5	7.4	0.630
Program for childhood onset disease is available for CM	3	9.4	7	10.3	
No program is available for CM	22	68.8	50	73.5	
Others	2	6.3	4	5.9	

CHD, congenital heart disease; CM, cardiomyopthy; JNCVD-ACHD, Japanese Network of Cardiovascular Departments for Adult Congenital Heart Disease.

for DCM cases, while almost 60% of children's hospitals reported a 1–24% rate (**Supplementary Figure**). Similar trends were observed for the other CM types except for ARVC. The correlation between the number of patients and the transfer rate revealed a significant increase in transfer rate with the number of cases, except for CMs associated with systemic diseases (**Table 2**). The number of ARVC cases was too small to be subjected to the correlation analysis. Across all CM types, the transfer destination was mostly the cardiology department, predominantly within its facility, followed by the cardiology departments in other facilities (**Figure 3**).

Transfer Policy for Patients With Childhood-Onset CMs and CHDs

Facilities with a transfer policy for patients with CHD tended to have the same policy for patients with CMs (P<0.001; **Table 3**). There were divergent responses to the questions regarding where patients with CM and CHD should be transferred. The highest number of facilities (23%) responded that "patients with CHD should be transferred to an ACHD-specialized facility and patients with CM to a cardiology department", while the smallest percentage of facilities (11%) responded that "patients with CHD should be transferred to an ACHD-specialized facility and patients with CM to a facility specialized in severe heart failure and/or arrhythmia". When compared by facility types, 38% of children's hospitals responded that "patients with CHD should be transferred to an ACHD-specialized facility and patients with CM to a facility specialized for severe heart failure and/or arrhythmia" (**Supplementary Table 2**).

Need and Availability of Transition Program

Fifty-five (55%) facilities responded that patients with CM, as well as those with CHD, need transition programs. However, only 13 (24%) out of these facilities actually offered a transition program for patients with CM. Nine (69%) of the 13 facilities applied the program for patients with CHD and those with CM (**Table 4**).

When compared by facility type, all 13 children's hospitals answered that a transition program for CM was necessary, and 8 (62%) offered such a program (P=0.008; **Supplementary Table 1**).

Furthermore, the JNCVD-ACHD participating facilities were considered to possess the ACHD-treating system, including the (pediatric/adult) cardiologists actively treating CHD/ACHD. Therefore, to examine whether these cardiologists influenced the transfer policy of the facilities, we evaluated the association between JNCVD-ACHD participation, transfer policy, and the availability of transition programs in each facility. We found that 21 (65.6 %) JNCVD-ACHD participating facilities were found to have a transfer policy for patients with CM, which was slightly higher, but not significant, than that for non-JNCVD-ACHD participating facilities (58.8%, P=0.680, **Table 5**). Additionally, only 25% of JNCVD-ACHD participating facilities had a transition program for patients with CM (**Table 5**).

Discussion

To the best of our knowledge, this is one of the first studies to identify the real-world status of transitional care for childhood-onset CM in Japan, as compared to patients with CHD. This study yielded 3 important findings: (1) the transfer rates for all CM types were low; (2) facilities transferring patients with CHD tended to transfer patients with CM as well; and (3) transition programs are recognized as necessary but are not sufficiently offered. Each of these findings will be discussed in the context of the existing literature.

Low Transfer Rates

The transfer rates for patients with CM approaching adulthood were remarkably low, with only <5% of facilities transferring all such patients to suitable adult healthcare settings. Reportedly, 74% of the patients with ACHD in Europe and the United States are transitioned to adult care.[19] However, in Japan, the rate is low; nonetheless, the percentage of patients with CHD who are transferred to adult cardiology departments after reaching adulthood is approximately 50%.[20] The transfer rate for CM cases was lower than that of ACHD. One reason for this is that most patients with ACHD are now under the care system in Japan and are therefore likely to be transferred to the already established ACHD-specific departments. In contrast, patients with CM are transferred to the general cardiology department, a specialist facility for severe heart failure, or a specialist facility for arrhythmia, depending on the severity of their condition and the opinions of the caring physicians. However, there may be patterns in which patients drop out during the selection of a new facility, during or following transfer to a facility with an adult care setting, such as general cardiology or a special facility for heart failure or arrhythmia.

Children's hospitals demonstrated higher transfer rates, which seemed inevitable owing to the medical insurance system in Japan; however, it would be challenging to address adult-specific conditions and complications in the management of pediatric hospitals.[21] Despite the intention to facilitate the transition process, the actual transferring of patients with childhood CM fell significantly below expectations in the majority of the facilities. The reasons for this discrepancy between intent and performance possibly include the lack of a transition program and system with adult cardiology departments as a transfer destination.

Facilities Transferring CHD and CM

As shown in **Table 3**, facilities that transferred patients with CHD were more likely to transfer those with CM. JNCVD-ACHD participating facilities showed a slightly higher rate of transition programs and the number of patients with CM transferred than non-JNCVD-ACHD facilities, although the number of such facilities was low (**Table 5**). Even in the JNCVD-ACHD facilities, where most of the patients with CHD are supposed to be transferred, the percentage of those providing a transition program for patients with CM is low (25%; **Table 5**). This implies that the transition system was not utilized for all patients, but was restricted to patients with some specific diseases represented by CHD. Generally, the transition in patients with CHD is systematically more advanced than that in patients with other diseases. In 2000, the first guideline for ACHD treatment in Japan was published. Since then, it has been updated periodically. The latest version emphasizes the importance of transition and transfer.[22] In a statement on transitional care for all patients with childhood-onset chronic diseases proposed by the Japan Pediatric Society in 2014,[23] the transition/transfer system for patients with CHD was utilized as an example for discussion, suggesting that the field of CHD has been a frontrunner in the area of transition and transfer.

There are several reasons why transition/transfer systems have progressed only in the field of CHD. First, the incidence of CHD (approximately 1 in 100) is much higher than that of childhood-onset cancers (approximately 1 in 10,000), which span many medical specialties (mainly hematology, neurology, and rarely cardiology), suggesting a very small number of patients with cancer in one specialty. Furthermore, approximately 95% of the children with CHD could survive into adulthood, whereas the survival rate of children with cancer is relatively low (80%).[24] As a result, the number of patients with ACHD is expected to be over 450,000, which is approximately a 10,000 per

year increase in Japan.[25] In the 2020 report on the aggregate results of the Childhood Occurrence of Heart Disease Study 2020, the number of patients with CHD was 9,701, whereas the number of patients with CM was 223.[18] Among the various CMs, DCM, HCM, RCM, and LVNC, which have a high prevalence, tended to have higher transfer rates at facilities with large numbers of patients (**Table 2**). A large number of patients can contribute to the development of a transition/transfer system. As for RCM, although the total number of patients is small, the transfer rate is thought to be higher than that of other CMs. As shown in **Figure 3**, patients with RCM were transferred to their own cardiology department or a facility specializing in severe heart failure. Since patients with RCM are often in a severe condition, requiring heart transplantation, facilities treating a certain number of patients may be forced to transfer their patients. Cardiology is the basic care specialty for patients with CM. Nonetheless, neither transitional care nor specific transfer has been widely carried out for CM (**Supplementary Tables 1**,**2**). The small number of patients with CM is one reason why the cardiology transition/transfer system was founded only for CHD. Another reason may be that the knowledge of various CMs is considered common knowledge for adult cardiologists, which is opposite to the recognition of CHD, where specialized knowledge is crucial. From these points of view, it might be proposed that transitional care for patients with CM could adopt methods similar to those used for CHD. This would involve sending patients with CM initially to the general cardiology department in any available healthcare facility. The only difference will be the specific transfer destination.

Since patients with CMs consist of those with many types of diseases ranging in severity from mild to severe or even lethal, a selective and secondary transfer approach could be implemented. Patients might be directed to general cardiology departments, facilities specializing in severe heart failure, or institutions with significant expertise in managing arrhythmias or specific types of CM. Prior to the transfer, patient education (transitional care) should be offered to individuals with CMs and, indeed, to all patients with childhood-onset diseases. This ensures that they receive optimal care and can achieve their highest potential throughout their lives. Adult cardiologists are well acquainted with CMs, and it may be sufficient to employ not only the transfer system designed for patients with ACHD but also the established transitional care system for patients with ACHD. However, certain adjustments may be necessary before its implementation.

Lack of Transition Programs for Patients With CM

Although 92% of facilities acknowledged the necessity of providing a transition program to patients with CM, only 19 (21%) offered a transition program, of which 10 (53%) focused their CHD transition program on patients with CM (**Table 4**). Notably, facilities offering transition programs for patients with CHD exhibited the same trait for patients with CM. Transition programs for CHD are designed at each facility, both nationally and internationally, and include elements such as determination and referral to an adult healthcare setting, improvement in patient knowledge of the disease (current condition, medications, and potential future complications), self-management, limitations in daily living, available social security, and self-advocacy.[8,16,26] Taking into account the content of the transition program, it is plausible to suggest that if there exists a program or system for CHD, such could be applied to patients with cardiovascular diseases, including childhood-onset CM (**Table 4**). There is a need for transitional care for all childhood-onset chronic diseases, some of which are common and disease specific. Transition programs for patients with CHD can be widely applied, with the exception of transfer destinations. It is important to promote awareness of the need for transitional care and create a program for cardiovascular diseases based on a program for patients with CHD to hasten the establishment of a system of transitional care for cardiovascular diseases in general.

Since transition encompasses the transfer itself and the provision of independence support, patient education plays a pivotal role in facilitating seamless transition/transfer. In the United States, a 2011 joint statement issued by pertinent societies stipulated that transition programs should commence as early as age 12–14 years for all young adults.[27] Several studies have demonstrated that transition programs enhance transition readiness and yield diverse psychosocial benefits in patients with childhood-onset chronic diseases. An investigation involving adolescents with CHD revealed that face-to-face and online education provided by nurses regarding the disease and communication with healthcare professionals enhanced transition readiness and disease knowledge.[15,28] As a transition without adequate independence support is unlikely to succeed, the development of comprehensive adult transition programs is indispensable. The results of this study suggest that transitional care for CM has not yet been developed and that there is a need to collaborate with the CHD field.

Study Limitations

The present study has some limitations. First, our focus was solely on transitional care within pediatric departments; thus, we did not examine the extent of collaboration between these departments and other departments within each facility or with external facilities. Transitional care requires the involvement of both pediatric and adult cardiologists within the same facility or across multiple facilities. Therefore, we plan to conduct a survey targeting recipient cardiologists. Second, the responses regarding the number of patients and transition performance were assessed using a 5-point scale rather than an exact number. Due to the prioritization of response rates and the absence of mandatory reporting of precise internal data on the number of patients and transition rates, an accurate estimation may be challenging. Furthermore, although we inquired about the basic transition policies of all facilities, we did not specifically inquire about individual measures, such as patient severity or access to medical care. The questions posed by facilities have inherent limitations.

Conclusions

To the best of our knowledge, this is the first study to evaluate the status of transitional care for patients with childhood-onset CM compared with those with CHD. This study revealed the low transfer rates and limited availability of transition programs for patients with CM without expectations of future progress under the current situation. Collaboration with the CHD field could help develop successful and specific transition/transfer pathways in the field of CM.

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Disclosures

The authors have no conflicts of interest to declare.

IRB Information

The study protocol was approved by the Ethics Committee of Tokyo University Graduate School of Medicine and Faculty of Medicine (reference no. 2022377NI).

Data Availability

The deidentified participant data will not be shared.

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Supplementary Files

Please find supplementary file(s);
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