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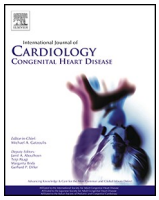

Transition of care for adolescents and young adults with Kawasaki disease: An international survey

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1. Introduction

Kawasaki Disease (KD) is an inflammatory febrile illness of childhood and the leading cause of pediatric acquired heart disease in developed countries [1]. Coronary artery aneurysms (CAA) develop in approximately 25% of children without treatment. However, timely diagnosis and treatment reduce the risk of CAA to under 5% [1]. CAA can potentially lead to myocardial infarction, need for coronary artery intervention, heart transplantation, or death during childhood [2]. Furthermore, the risk of cardiovascular complications accompanies the patient into adulthood. Among young adults with a history of KD in childhood, or a history of a KD-compatible-illness, angina, acute MI, congestive heart failure, claudication, ventricular arrhythmias, need for percutaneous coronary intervention or coronary artery bypass grafting, and cardiovascular death are well described [3–6]. Therefore, adolescents and young adults with a history of KD in childhood complicated by CAA require lifelong expert cardiology care [7,8].

Transition of care has been defined as "the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented healthcare systems." [9] Transition includes, but is not limited to the *transfer* from pediatric to adult care, which is when the responsibility for care is handed over from a pediatric provider to an adult provider. Transition and transfer are of growing importance in the field of KD given the lifelong care needs of young adults with CAA. However, most adult cardiologists have very little experience with KD and may accordingly lack confidence in the management of this patient group. Furthermore, although adult cardiologists are very experienced in the management of atherosclerotic cardiovascular disease, CAA are pathologically unique and require specific expertise.

To ensure uninterrupted medical care between childhood and adulthood for young adults with CAA, pediatric and adult health care providers need to establish coordinated transition and transfer protocols. However, the optimal destination within adult cardiology for these patients is unknown and may differ from one jurisdiction to another. Problematic transfer of KD patients from the pediatric to adult setting was highlighted in a Japanese multicenter survey [10]. Among members of the Japanese Society of Kawasaki Disease, 16/48 (40%) of respondents reported that they had patients who had been lost to follow-up despite having CAA. A recent registry report from Japan of

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798 hospitalizations highlights two age peaks of KD patients with CAA having cardiac events, specifically 15-19 year olds and 35-39 year olds [11]. Forty percent of patients with an acute coronary syndrome were current smokers, highlighting the co-existence of preventable cardiovascular risk factors in this population. These studies highlight the need for planned and well-coordinated cardiology follow-up in adulthood in this population.

Adolescent and young adult (AYA) patients have the complex task of learning to manage their health independently from their parents/guardians. This is particularly important for those with complex medical needs including those with KD and CAA. Having some knowledge of KD and their heart, knowledge of potential late complications, knowledge of cardiovascular risk factors and how to prevent them, and self-management skills (e.g., how to fill a prescription, how to make a medical appointment) are essential to avoiding lapses in care. Development of this knowledge and skillset requires active facilitation by pediatric providers, ideally beginning in early adolescence. Adult providers also share in this responsibility, as the process of transition is not complete for many patients until years after they have arrived in adult care. Although the evidence base supporting transition programs in congenital heart disease is well established [12–15], there is a lack of evidence regarding transition programming in KD.

To address these knowledge gaps, we sought to 1) describe the opinions of pediatric and adult cardiologists regarding the most appropriate transfer destination of patients with KD and CAA, and 2) describe the perceived needs for transition resources among pediatric and adult cardiology providers.

2. Methods

Study design and participants: We conducted an international web-based cross-sectional survey of pediatric and adult cardiologists, and nurse practitioners and physician assistants practicing pediatric or adult cardiology. The survey consisted of multiple-choice questions across 3 sections: i) respondent demographics, ii) preferred transfer destination for young adult patients with KD and CAA, and iii) access to transition resources within their program. With respect to section iii), respondents who self-identified their clinical practice as limited to pediatric cardiology were directed to a different set of questions than those who stated their clinical practice included adult patients. A free-text question was also asked of all respondents, allowing them to provide additional comments and insights about transition of KD care and adult KD management. A copy of the survey is available as a Supplementary Material. Participants were excluded if they completed demographic questions only.

A link to the survey was distributed by email to members of multiple professional organizations and medical consortia including the International Kawasaki Disease Registry, the Association for European Paediatric and Congenital Cardiology, the Japanese Society of Adult Congenital Heart Disease, the Japanese Society of Kawasaki Disease, the Kawasaki Disease Arab Initiative (KAWARABI), the Enfermedad de Kawasaki en América Latina (REKAMLTINA), the India Kawasaki Disease Society, the European Kawasaki disease research collaboration (recently known under EUROKIDS**),** the Korean Society of Kawasaki Disease, the Asia Pacific KD Association, the Kawasaki Red Académico Colaborativo Español (KAWA-RACE) (Societies & Consortia | IKDS), the Asia-Pacific adult congenital heart disease association, PediHeartNet [16], an e-mail group of North-American pediatric cardiologists, and the Canadian Pediatric Cardiology Association. Return of a completed survey was considered to represent implied consent. All responses were anonymous, with no link possible between responses and email addresses or other personal identifying information. Respondents that completed only demographic data were excluded from analysis. The study was approved (August 2024, authorization # 2025-7750) by the research ethics board at the Centre Hospitalier Universitaire Sainte-Justine in Montreal, Canada.

Statistical analysis: All data are categorical in nature and presented as proportions. Individuals who did not provide responses to a specific question were not counted in the analysis of that question. Fisher's exact test was used to determine whether specialty, country, number of years in practice, or practice type (academic, non-academic, community-based) were associated with a response of recommending that ACHD specialists are the most appropriate providers. Multiple logistic regression was performed using a stepwise selection procedure. All tests were two-sided and evaluated at a 0.05 level of significance.

3. Results

There were 257 respondents from 29 countries, 153 complete and 104 incomplete replies. Participant demographics are described in Table 1. Most participants (109/153, 71%) were pediatric cardiologists, and most had been in practice for >15 years. Two-thirds were in a hospital-based academic practice. Among adult cardiology respondents, there was a predominance of CHD specialists (34/44, 77%) and a significant proportion (18/44, 41%) indicated they were involved in KD research either in the past or present.

Preferred transfer destination: Respondents were asked "in your opinion, which providers are the most appropriate to manage adult patients with KD and CAA?" The largest proportion of respondents (42/108, 39%) indicated that adult CHD (ACHD) specialists were the preferred group. However, there were significant differences between countries. Among Japanese respondents, 2/44 (5%) stated that ACHD specialists are the preferred providers of adult patients with KD and CAA, vs. 15/34 (44%) among US respondents ($p < 0.001$). There was no difference in the distribution of responses between pediatric versus adult cardiology providers (Table 2). The most common reasons for preferred transfer destinations are summarized in Table 3. "Established relationships with pediatric programs, facilitating transition and transfer", "experience managing ischemic heart disease" (relative to pediatric cardiologists) and "experience managing young adults" were the most common reasons for preferring that ACHD providers assume responsibility for the care of young adults with KD and CAA.

On binomial multivariate logistic regression, respondents from Canada and the USA were much more likely than respondents from Japan to select ACHD providers as their preferred destination for

Table 1
Respondent characteristics (n = 153).

Characteristic		N = 153 (100%)
Clinical practice	Pediatric cardiologist	109 (69.4)
	ACHD physician	18 (11.5)
	Both pediatric cardiology and ACHD physician	16 (10.2)
	General adult cardiology	5 (3.2)
	Adult interventional cardiology	5 (3.2)
	NP or PA with practice in ACHD	0
Location of practice	Canada	12 (8.3)
	United States	34 (23.6)
	Japan	44 (30.6)
	Europe	19 (13.2)
	Middle East	17 (11.8)
	[a]Other jurisdictions	18 (12.5)
	Not provided	9 (5.9)
Years in practice	<5	27 (17.7)
	5-10	20 (13.1)
	11-15	19 (12.4)
	>15	87 (56.9)
Practice type	University-based academic practice	102 (66.7)
	Hospital-based practice non-academic/ community-based practice/other	51 (33.3)

ACHD = adult congenital heart disease; NP = nurse practitioner; PA = physician assistant.

[a] Other jurisdictions = Australia, Libya, Mexico, Morocco, Russia and South Korea.

Table 2
Preferred specialty to manage adult patients with KD and CAA: Pediatric versus adult providers.

Preferred specialty	Pediatric cardiologists N = 108 (100%)	Adult cardiologists[a] N = 28 (100%)	p-value[b]
Pediatric cardiologists	13 (12.0)	3 (10.7)	0.46
ACHD specialists	42 (38.9)	11 (39.3)	
General adult cardiologists	17 (15.7)	8 (28.6)	
Adult interventional cardiologists	29 (26.9)	6 (21.4)	
Other	7 (6.5)	0	

ACHD = adult congenital heart disease.
[a] Includes ACHD, general adult cardiologists, and adult interventional cardiologists; excludes participants who classified their practice as both pediatric cardiology and ACHD.
[b] Fisher's exact test.

patients with CAA (odds ratio 12.6, 95% CI 2.6, 60.7, p = 0.002 and 9.1, 95% CI 2.8, 29.5, p < 0.0001, respectively) (Table 4). Likewise, participants from the "Other" countries (Australia, Libya, Mexico, Morocco, Russia, and South Korea) were also more likely than respondents from Japan to recommend an ACHD provider (OR 4.5, 95% CI 1.2, 17.1, p = 0.03). However, this was not true of participants from Europe or the Middle East.

Transition Resources (Pediatric Cardiologists): Among pediatric cardiologists, only 39/107 (36%) indicated their practice setting has a transition program. Of these, the transition program most often included education for the patient about KD, education about potential future complications of KD, and information about self-management skills (Supplementary Table 1).

Transition resources desired by respondents are listed in Supplementary Table 2. Barriers most faced with respect to implementation of a transition program were lack of human resources (nursing, social work, etc.) for 70/108 respondents (65%), lack of time (35/108 respondents, 32%) and insufficient compensation for transition activities (35/108 respondents, 32%).

Transition Resources and Knowledge of KD (Adult Cardiologists): Most adult cardiology respondents had few patients with KD and CAA in their practice. Twenty (45%) reported only 1-5 patients in their practice, 10 (23%) reported 6-10 patients, and 7 (16%) reported >10 patients. However, 41/44 (93%) felt "moderately prepared", "quite prepared", or "very prepared" to accept adults with KD from pediatric practice. Likewise, most respondents (34/44, 77%) felt "moderately", "quite", or "very familiar" with the medical literature related to invasive management of CAA. The majority (33/44, 75%) felt that it was very important that training curricula in ACHD include formal objectives in KD with an additional 6/44 (14%) indicating that this may become important in the future.

Short answer questions: Both pediatric and adult cardiology respondents were asked to provide additional insights or comments about transition and transfer of adolescents and young adults with KD and CAA. Responses were focused predominantly on the lack of experience and expertise of adult cardiologists with KD, and the lack of resources to help patients with transition. Two representative comments from pediatric cardiologists were.

- "The most important factor for care of adults to me is to ensure a provider with knowledge of KD and their underlying CAA/coronary artery disease is available to adult centers with CA interventions. Our ACHD team regularly works with the adult cardiac team that would do ACS/coronary interventions if needed."

Table 4
Binomial multivariate logistic regression analysis of the association between provider demographics and selection of ACHD specialists as preferred choice for managing KD and CAA.

	Adjusted OR (95%CI)			P-value
	Selected ACHD specialist vs. did not select ACHD			
Effect	OR	95% CI		
Pediatric cardiologist vs. all other providers	0.51	0.21	1.26	0.15
Location of practice				
Japan (ref)				
Canada	12.55	2.59	60.74	0.002
United States	9.11	2.82	29.47	<0.0001
Europe	2.60	0.66	10.16	0.17
Middle East	3.00	0.77	11.76	0.11
Other	4.46	1.16	17.07	0.03
Years in Practice				
<5 (ref)				
5-10 years	1.62	0.43	6.00	0.47
11-15 years	0.96	0.24	3.87	0.95
>15 years	0.94	0.33	2.70	0.91
Practice Type				
University-based academic practice (ref)				
All other practice types	1.22	0.52	2.85	0.65

Table 3
Most common reasons for preferred specialty.

Preferred specialty	Most common reasons (choose up to 2 best reasons)	Pediatric cardiologists N = 109 (100%)	Adult cardiologists[a] N = 28 (100%)	p-value[b]
Pediatric cardiologists	Experience managing KD in children	13 (12)	2 (7)	0.75
	Patients reluctant to leave pediatric setting	2 (2)	0	
	Parents reluctant to leave pediatric setting	1 (1)	0	
	KD is different from atherosclerotic CVD	5 (5)	2 (7)	
ACHD specialists	Experience managing young adults	20 (18)	7 (25)	0.56
	Experience managing ischemic heart disease¶	25 (23)	4 (14)	
	Established relationships with pediatric programs, facilitating transition and transfer	28 (26)	6 (21)	
	Young adults no longer want to be followed in children's hospitals	5 (5)	0	
General adult cardiologists	Experience managing ischemic heart disease	17 (16)	8 (29)	0.34
	Greater availability compared to ACHD specialists	11 (10)	3 (11)	
	Young adults no longer want to be followed in children's hospitals	2 (2)	3 (11)	
Adult interventional cardiologists	Provide catheter-based coronary artery intervention	24 (22)	4 (14)	1.00
	Experience managing ischemic heart disease	25 (23)	5 (18)	
	Young adults no longer want to be followed in children's hospitals	2 (2)	0	

ACHD = adult congenital heart disease; CVD = cardiovascular disease; KD= Kawasaki disease.
[a] Includes ACHD, general adult cardiologists, and adult interventional cardiologists; excludes participants who classified their practice as both pediatric cardiology and ACHD.
[b] Fisher's exact test ¶Relative to pediatric cardiologists.

- "KD transition is really a subset of all pediatric to adult transitioning. We started a regular ACHD transition program that eventually lost support, and I think at least the process (if not the destination) should be incorporated into a larger program."

With respect to management, two representative comments from adult cardiologists were.

- "I feel that adult cardiologists should be well suited to care for this. The challenge is to find someone who will take the time to read [the] guidelines and work with interventional cardiology in a collaborative manner."
- I believe that a combined clinic involving intervention & ACHD is ideal, as we started …"

4. Discussion

Key findings of this international study were: 1) ACHD specialists were more frequently rated as appropriate providers for adult patients with KD, relative to other cardiologists, with the most commonly provided rationale being their established relationships with pediatric programs, facilitating transition and transfer, their greater experience (relative to pediatric cardiologists) at managing ischemic heart disease, and their experience working with young adults (with CHD); 2) there were regional differences in the preferred transfer destination of adult KD patients, with respondents from Canada and the United States being significantly more likely than respondents from Japan to indicate a preference for ACHD providers as the ideal destination; 3) only 1/3 of pediatric cardiologists indicated that their practice setting had a transition program, and 4) most adult cardiology respondents agreed that it was "very important" for ACHD training curricula to include formal learning objectives in KD.

To our knowledge this is the first study to determine the perspectives of pediatric and adult cardiologists regarding the ideal providers for adults with a history of KD in childhood complicated by CAA. Although most respondents (71%) were pediatric cardiologists, only a minority (12%) of them felt that their specialty should continue to manage these patients once they reached adulthood. This finding is in keeping with recent Scientific Statements from the American Heart Association which emphasize the importance that medical teams that care for these patients establish health care transition plans as these children become adults [1,17]. Adult patients have unique health care needs that most pediatric cardiologists are not experienced with, including potential exposure of their patients to teratogenic medications (e.g., warfarin) during pregnancy, and acute coronary syndromes.

This study highlights some regional differences in preferred transfer destinations for young adults with KD, from the perspective of providers. Almost half of respondents felt that either a general adult cardiologist or an adult interventional cardiologist was an acceptable provider for adult patients with KD and CAA (Table 2), reflecting a broad range of perspectives. Among Japanese respondents, only 5% stated that adult CHD cardiologists are the preferred providers of adult patients with KD and CAA, compared to 44% of US respondents. This may be due to the later development of adult CHD as a specialty in Japan relative to the US [18]. Alternatively, this may reflect the unique clinical environment in Japan, where KD is common [19] and adult general cardiologists and interventional cardiologists are generally more familiar with its long-term coronary sequelae. Consequently, Japanese respondents may perceive follow-up by general adult cardiologists, or even family physicians for lower-risk patients, with referral to specialized centers when necessary, as an appropriate model of care rather than routine referral to ACHD specialists. However, this interpretation remains speculative, as our survey did not specifically explore the reasons underlying these preferences.

With respect to preferred transfer destination, no single model will work for all centers, and it may not be necessary or practical for all patients to be followed exclusively in highly specialized centers. However, patients with severe cardiovascular sequelae in adulthood will require access to multidisciplinary care including interventional cardiologists, heart failure specialists, transplant cardiologists, and electrophysiologists [11]. Regardless of the "ideal" subspecialty to manage these patients, empowering patients to understand and accurately communicate their medical history will help patients obtain the care they need.

This study focused on the long-term management of KD in adults, which is typically centralized in specialized centers, regardless of whether patients are managed by an ACHD or a non-ACHD specialist. However, the acute management of acute coronary syndromes is highly time-sensitive and therefore depends on the availability of emergency cardiovascular services near the patient's home. This challenge highlights the importance of patients knowing where and when to seek emergency care, having some knowledge of their health condition that they can communicate to emergency providers, a health summary or "passport" summarizing key medical history, and a list of current medications and recent modifications in treatment strategy, including anticoagulation and therapeutic target range. The above should all be addressed by pediatric cardiology programs through careful and purposeful transition planning prior to transfer of patients to adult cardiology care.

A minority of pediatric cardiologists reported that their practice setting has a transition program. Unfortunately, this is consistent with data about transition practices of pediatric programs for patients with CHD, with only 30-40% of programs self-reporting that they provide structured preparation for patients and family [20,21], despite the evidence that transition programs for AYA with CHD increase disease knowledge and self-management skills [22–27]. More importantly, AYA and their parents experience significant anxiety and fear regarding transition, and desire structured programs. The transition needs of AYA with KD, as described by Chahal and colleagues in a large survey of KD patients and parents [28], have many similarities to those having CHD. These include the need to learn about their condition including future potential cardiac complications. Both groups also need to acquire simple self-management skills, such that they can effectively manage their health in partnership with their care providers. Accordingly, it is simple to adapt many aspects of transition care for patients with CHD to those having KD, and to extend CHD transition programs to a broader cardiac transition program that is inclusive of AYA with acquired cardiac disease. Pediatric and adult cardiac providers should work together to effectively establish a plan for transition and transfer within each tertiary center, as previously described by the Toronto program [29]. This study has some limitations. This includes a low number of adult cardiology respondents, and among the adult cardiology respondents, over-representation of ACHD providers (71%). This reflects the organizations through which the survey was distributed. Therefore, the data are most reflective of the preference of pediatric cardiologists and ACHD cardiologists rather than general adult cardiologists. Cardiologists with an interest in KD may have been more likely to participate, resulting in selection bias. Almost half of respondents indicated that they participate in KD research, suggesting that the respondents were not representative of the broader cardiology community. Data was based on self-report, with the potential for social desirability bias. Questions about the availability of medical resources were not asked, limiting the ability to make conclusions about why responses were influenced by country of residence.

In conclusion, this international survey of pediatric and adult cardiologists demonstrates that only 1/3 of pediatric cardiology providers had a transition program in their practice setting to support adolescents preparing for the adult healthcare system, demonstrating a major care gap for adolescents with KD and CAA. ACHD specialists were the preferred providers in most jurisdictions for young adults with KD and CAA, despite KD being an acquired rather than congenital condition. There was geographic variation, with ACHD providers more favored in

Canada and the US relative to Japan, possibly reflecting greater experience with KD among general and interventional cardiologists in Japan compared to North America. Ultimately, who manages these patients is probably less important than ensuring that all KD/CAA patients receive transition support and that they are cared for by a cardiology provider who has the interest and skills needed to do so. International KD-specific guidelines are needed with respect to transition curriculum development, enabling pediatric and adult cardiologists and allied healthcare providers to support this population.

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CRediT authorship contribution statement

Andrew S. Mackie: Writing – review & editing, Writing – original draft, Project administration, Methodology, Formal analysis, Data curation, Conceptualization. **Adriana Tremoulet:** Writing – review & editing, Project administration. **Anitha S. John:** Writing – review & editing. **Teiji Akagi:** Writing – review & editing, Project administration. **Kenichiro Yamamura:** Writing – review & editing, Project administration. **Lucy Eun:** Writing – review & editing, Project administration. **Alain Fraisse:** Writing – review & editing, Project administration. **Nagib Dahdah:** Writing – review & editing, Project administration, Methodology, Conceptualization.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Appendix A. Supplementary data

Supplementary data to this article can be found at https://doi.org/10.1016/j.ijcchd.2026.100701.

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