Improvements in surgical and medical care have markedly changed the demographics of congenital heart disease (CHD). In a Canadian population-based study, 66% of all persons living with severe CHD in 2010 were adults. Following the development of Canadian guideline for adult CHD (ACHD), there were increased referrals to ACHD centers and a temporally associated decrease in mortality. Yet how patients transfer from pediatric to adult care varies greatly in many communities. Some patients transfer to regional ACHD care centers, some to general adult cardiologists and others maintain longitudinal care with their pediatric cardiologists.

In this issue of the Journal, Ochiai and colleagues seek to better understand the variation in transfer practices. The investigators surveyed pediatric cardiologists regarding current ACHD care within their own departments, transfer practices and if their pediatric facilities intended to be ACHD centers. There was a robust response, with replies from 113 of 149 centers across Japan. A majority of responders (54%) believed their facility would serve the role of an ACHD, including 5 free-standing pediatric hospitals. There was a high degree of variability in the volume of care currently being delivered. Among all respondents, 43% of facilities followed fewer than 50 patients per year and 54% had fewer than 10 ACHD surgeries per year; 26 centers had more than 200 patients per year and were estimated to be seeing 80% of the ACHD population. Only 3 centers performed more than 50 ACHD surgeries annually. Among the 61 centers intending to serve as ACHD centers, 9 met the minimal criteria set by the authors and only 1 met all of the optimal criteria.

Regarding current transfer patterns, 43% (49 of the 113 facilities) either routinely transfer their pediatric patients or consider transfer on a case-by-case basis. Regarding future intentions, 49% (55 facilities) aspire to transfer to dedicated

**Figure.** Map of Japan showing regional adult congenital heart disease (ACHD) care centers and populations. (Reproduced from Ochiai R, et al.)

The opinions expressed in this article are not necessarily those of the editors or of the Japanese Circulation Society.
Received March 30, 2016; accepted March 31, 2016; released online April 8, 2016
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ISSN-1346-9843 doi: 10.1253/circj.CJ-16-0290
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ACHD facilities while 30% (34 facilities) would prefer to keep them within a pediatric setting.

These percentages are relatively similar to a 2009 survey of pediatric cardiology programs in the United States. Among 69 centers that participated in the survey, 36% (25 of 69 centers) had an optional transfer policy, 38% (26 centers) had a mandatory transfer policy and 26% (18 centers) did not intend to transfer patients.

Although there is anticipated benefit from dedicated ACHD centers, there is controversy regarding whether this care should be centered at a pediatric or an adult institution. In analyses of the Nationwide Inpatient Sample, a cross-sectional database of approximately 20% of the non-federal hospitals in the USA, mortality was lower for pediatric heart surgeons operating on adult patients at pediatric centers vs. pediatric heart surgeons operating on adults at adult hospitals. Non-pediatric heart surgeons had higher mortality rates than their pediatric colleagues. There was a survival advantage with increasing surgeon annual pediatric volume. Favorable surgical results have been obtained by congenital heart surgeons at high-volume adult hospitals with dedicated ACHD teams. Overall, the data suggest a benefit to higher volume congenital heart surgery centers. High volume alone does not insure quality, but it can justify expenditure of resources towards specialized personnel and equipment, building team experience, and refining processes.

Pediatric heart centers may have extensive expertise with the surgical, interventional, electrophysiological and imaging aspects of CHD, but they often have limitations for caring for adults beyond the scope of their disease. Non-cardiac comorbid conditions may warrant adult specialist care. Increasing numbers of women with CHD are becoming pregnant and frequently warrant a team-based approach between ACHD specialists, high-risk obstetrical providers and obstetrical anesthesiologists. Patients with the Fontan circulation may develop complications from congestive hepatopathy that may be better addressed at a single institution. In many communities, it may be advantageous to develop a robust partnership between pediatric and adult institutions rather than trying to duplicate the resources of the other institution. The Figure elegantly illustrates the additional challenges of offering highly specialized resources in less densely populated communities. Coordination between local health centers and regional referral centers is likely necessary to achieve high-quality care across a wide geographic area.

Transfer from pediatric to adult congenital specialists should occur as the culmination of a multi-year process of transition education. Education should include anticipatory guidance regarding residual lesions, potential late sequelae, implications for vocation and lifestyle issues as well as contraceptive and pregnancy planning. The importance of lifelong care should be emphasized at a young age, as Mackie and colleagues demonstrated many patients fail to follow up with pediatric cardiology before adulthood. In their series, only 30% of patients with simple shunt lesions and 79% of patients with severe lesions were seen after the 18th birthday. Yet 93% of those patients still had contact with primary care or other physicians within the healthcare system.

This report significantly adds to the understanding of the current practices and perspectives of pediatric cardiologists in Japan. The findings will help inform collaborations between pediatric and adult providers striving to improve the outcomes for the rapidly growing number of adults with CHD.

References

1. Marelli AJ, Ionescu-Ittu R, Mackie AS, Guo L, Kendukuri N, Kaouache M. Lifetime prevalence of congenital heart disease in the general population from 2000 to 2010. Circulation 2014; 129: 1804 – 1812.
2. Karamlou T, Filote L, Ionescu-Ittu R, Abramowicz M, Khairy P, Therrien J, et al. Specialized adult congenital heart disease care: The impact of policy on mortality. Circulation 2014; 129: 1295 – 1299.
3. Ochiai R, Kato H, Akiyama N, Ichida F, Yoo A, Inuzuka R, et al. Nationwide survey of the transfer of adults with congenital heart disease from pediatric cardiology departments to adult congenital heart disease centers in Japan. Circ J 2016; 80: 1242 – 1250.
4. Hilderson D, Saiti AS, Van Deyk K, Verspagten A, Kovacs AH, Fernandes SM, et al. Attitude toward and current practice of transfer and transition of adolescents with congenital heart disease in the United States of America and Europe. Pediatr Cardiol 2009; 30: 786 – 793.
5. Karamlou T, Diggs BS, Person T, Ungereider RM, Welke KF. National practice patterns for management of adult congenital heart disease: Operation by pediatric heart surgeons decreases in-hospital death. Circulation 2008; 118: 2345 – 2352.
6. Karamlou T, Diggs BS, Ungereider RM, Welke KF. Adults or big kids: What is the ideal clinical environment for management of grown-up patients with congenital heart disease? Ann Thorac Surg 2010; 90: 573 – 579.
7. Kogon BE, Plattner C, Leong T, Kirshbom PM, Kanter KR, McConnell M, et al. Adult congenital heart surgery: Adult or pediatric facility? Adult or pediatric surgeon? Ann Thorac Surg 2009; 87: 833 – 840.
8. Wannes CA. Pregnancy and delivery in women with congenital heart disease. Circ J 2015; 79: 1416 – 1421.
9. Lu CW, Shih JC, Chen SY, Chiu HH, Wang JK, Chen CA, et al. Comparison of 3 risk estimation methods for predicting cardiac outcomes in pregnant women with congenital heart disease. Circ J 2015; 79: 1609 – 1617.
10. Trigas V, Nagdyman N, Pildner von Steinburg S, Oechslin E, Vogt M, Berger F, et al. Pregnancy-related obstetric and cardiologic problems in women after atrial switch operation for transposition of the great arteries. Circ J 2014; 78: 443 – 449.
11. Bhatt AB, Foster E, Kuehl K, Alpert J, Brabeck S, Crumb S, et al. Congenital heart disease in the older adult: A scientific statement from the American Heart Association. Circulation 2015; 131: 1884 – 1931.
12. Maxwell BG, Wong JK, Kin C, Lobato LR. Perioperative outcomes of major noncardiac surgery in adults with congenital heart disease. Anesthesiology 2013; 119: 762 – 769.
13. Maxwell BG, Fosler KL, Wong JK, Oakes DA, Kelly NE, Domino KB, et al. Factors contributing to adverse perioperative events in adults with congenital heart disease: A structured analysis of cases from the closed claims project. Congenit Heart Dis 2015; 10: 21 – 29.
14. Sable C, Foster E, Uzark K, Bjorlsen K, Canobbio MM, Connolly HM, et al. Best practices in managing transition to adulthood for adolescents with congenital heart disease: The transition process and medical and psychosocial issues: A scientific statement from the American Heart Association. Circulation 2011; 123: 1454 – 1458.
15. Mackie AS, Ionescu-Ittu R, Therrien J, Filote L, Abramowicz M, Marelli AJ. Children and adults with congenital heart disease lost to follow-up: Who and when? Circulation 2009; 120: 302 – 309.