

Often transferred, rarely transitioned: the current state of transition for young people with congenital heart disease

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Main text

Advances in diagnosis and care, especially early diagnosis and timely repair or palliation, have led to a substantial improvement in the long-term congenital heart disease (CHD) survival. The vast majority of individuals born with CHD nowadays reach adulthood. As a consequence, most of these patients will need to shift from paediatric to adult CHD (ACHD) care. There are two key elements in this process, commonly referred to as "transfer" and "transition". *Transfer* describes the handover of care from paediatrics to adult services; this should be smooth and timely, with efficient communication of information and a written care plan, thus, avoiding gaps in care. *Transition* reaches far beyond *transfer*. It is a longer, more comprehensive process including educating patients, preparing them for a lifetime with a chronic heart condition, ultimately aimed at optimising their survival and quality of life. Education is central to the process of transition. Education for families starts well before transition, i.e. at the time of diagnosis, and should prepare the parents for transition and the shift in responsibility to the patient. (1) Transition intensifies the education process, placing patients at the centre and empowering them to gain greater control over the actions and decisions affecting their health. It establishes a dialogue with the patient and sets the foundations for a life-long learning process that helps them accept shared responsibility for their health with their medical team. Education can help prevent obesity, dyslipidaemia, detraining, infective endocarditis and avoid loss to follow-up, all of which can have detrimental effects on outcomes. (2–4)

The study by Thomet et al. in this issue of the *International Journal of Cardiology* (5) highlights the variability of transition care provided to CHD patients, much of which falls below the standards advocated by various guidelines and expert statements. (1,6,7) It is, at least, somewhat reassuring that the majority of centres transfer their patients to adult services with two-thirds of centres surveyed transferring all their patients from paediatrics to ACHD services. Compared to a 2009 survey, however, the proportion of centres transferring CHD patients from paediatric to adult care has fallen by 15%. (8) Furthermore, the transfer process did not fulfill essential criteria and requirements set by practice recommendations.

It is even more disconcerting to observe that only 42% of centres had a structured transition service. This represents a *drop* in the number of centres offering formal transition programmes over the years. (3) Of centres providing transition, 20% started this process later than recommended, after the age of 16 years. Indeed, in many centres, there was a noticeable overlap in the age range provided for transfer and transition, perhaps implying that the two processes were (inappropriately) amalgamated. Alternatively, and perhaps of greater concern, this might suggest that these terms and concepts are not well understood.

The status quo of transfer and transition in CHD is far from ideal. An organised and structured transition is advocated by the ESC ACHD guidelines, although these recommendations do not provide requirements or standards that services should adhere to. The AHA/ACC guidelines go slightly further, defining transition as a structured process that should start in early adolescence or sooner and extend beyond 18 years of age in many patients, hence beyond transfer of care. The AHA has also published detailed expert consensus and recommendations on this topic, which were not, however, included in the updated practice guidelines. (1)

Perhaps the apparent reluctance of centres to adopt a structured transition approach reflects the lack of evidence demonstrating its efficacy. To date, there is a randomised trial involving 1 hour of education to adolescents with CHD. (9) Even though this intervention did not meet the standards of a structured transition, measurable effects were reported in terms of time

lapsed from last paediatric to first ACHD clinic, transition readiness, and health-related knowledge.

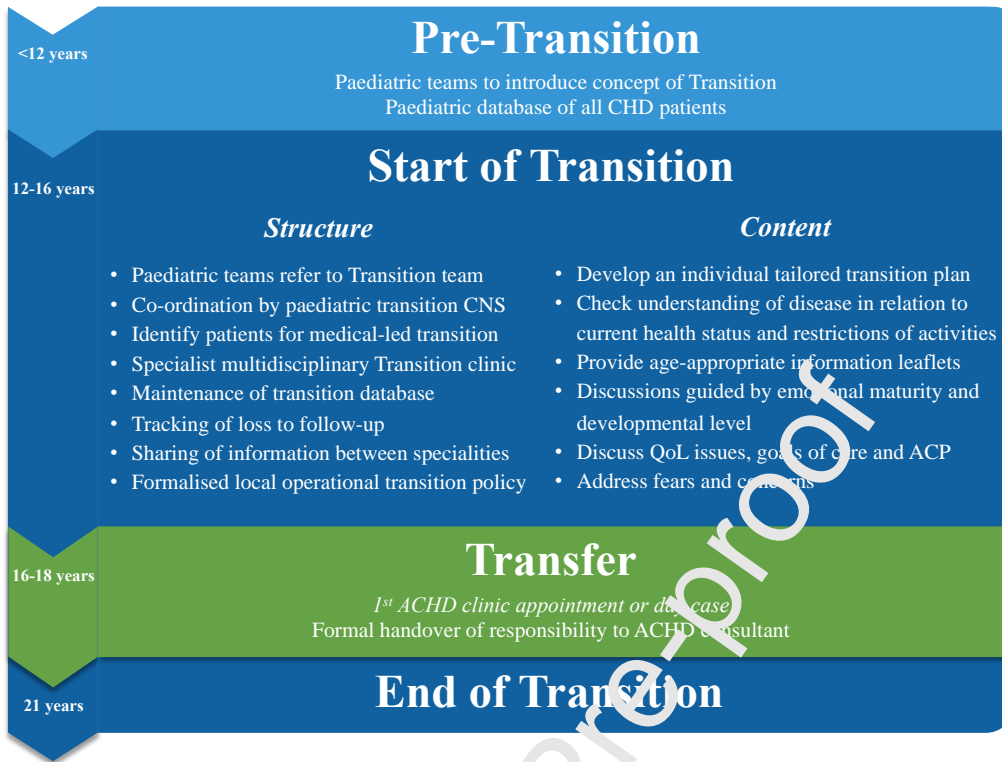
Structured transition services require significant resources and are poorly (or not at all) supported by insurance in some environments. These demands must be balanced against limited healthcare resources. The AHA Scientific Statement on managing transition in CHD described the development of an ideal transition program as a "laudable goal that may not be achievable in the current healthcare environment". (1) Setting up and maintaining a transition service is not easy and requires funds for training of healthcare providers in CHD and the care of adolescents and young adults, as well as support for a multidisciplinary team of doctors, nurses, psychologists, physiotherapists, social workers, and others. (6)

Clinical nurse specialists (CNSs) play a pivotal role in transition services and educating patients throughout their lives. Education for young patients cannot rely on a single encounter and cannot be achieved effectively during the, often brief, follow-up visits in a paediatric or adult CHD clinic. Education requires space and time. It also requires an open channel of facilitated communication between the patient and the nominated transition healthcare worker, who acts as an advocate and a reference for education opportunities, including online resources, service "open days" (e.g. visiting the ACHD team and facilities), and other group activities. While alternative personnel, such as volunteer, trainee patient advocacy associations, can contribute to patient education, given the presumed benefits of transition to this population's health and wellness, it stands to reason that such initiatives should be supported by insurance or government initiatives. Furthermore, volunteers could not replace the central role of a transition CNS, knowledgeable in CHD and the life-long challenges of living with chronic heart disease. Unfortunately, the role of CNS is not yet established world-wide and education often falls upon physicians, who may not be able to dedicate sufficient time to this important task – and are not adequately trained in many instances. Indeed, an average transition consultation in the study by Thomet et al. lasted 45 minutes, which is far longer than what is routinely available for physician-led consultations. Brief consultations may provide some benefit, but do not allow for a dialogue that will help patients make healthy choices based on their knowledge, ideas, and emotions.

The willingness of so many centres to participate in this survey by Thomet et al. shows the broad awareness of the importance of transfer and transition in CHD. Recognition that transfer is not equivalent to transition represents a first step. A structured transition to adult care should be a requirement and an important quality indicator for all paediatric CHD services (**Figure**). Perhaps a system of self-accreditation of CHD centres in terms of transition may facilitate the allocation of funds for the creation of transition services in all CHD centres. A structured transition and smooth transfer can ensure that no CHD patient is ever again lost between paediatric and adult services. Networks of hub-and-spoke CHD centres may be a solution, with larger CHD centres supporting smaller/peripheral services in providing a structured transition for their patients, facilitated by telemedicine (10). Indeed, the digital revolution that accompanied the disruption of services by the COVID-19 pandemic has opened possibilities for virtual education, which may be transformational for services that strive to educate young people.

References

1. Sable Craig, Foster Elyse, Uzark Karen, Bjornsen Katherine, Canobbio Mary M., Connolly Heidi M., et al. Best Practices in Managing Transition to Adulthood for Adolescents With Congenital Heart Disease: The Transition Process and Medical and Psychosocial Issues. *Circulation*. 2011 Apr 5;123(13):1454–85.
2. Kempny A, Diller G-P, Dimopoulos K, Alonso-Gonzalez R, Uebing A, Li W, et al. Determinants of outpatient clinic attendance amongst adults with congenital heart disease and outcome. *Int J Cardiol*. 2015 Oct 22;203:245–50.
3. Vonder Muhll I. Transition to adult care for adolescents with congenital heart disease - Is there a light at the end of the tunnel? *Int J Cardiol*. 2020 15;311:35–6.
4. Gurvitz M, Valente AM, Broberg C, Cook S, Stout K, Kay J, et al. Prevalence and Predictors of Gaps in Care Among Adult Congenital Heart Disease Patients (The Health, Education and Access Research Trial: HEART-ACHD). *J Am Coll Cardiol*. 2013 May 28;61(21):2180–4.
5. Thomet C, Schwerzmann M, Budts W, De Backer J, Chessa M, Diller G, et al. Transfer and transition practices in 96 European adult congenital heart disease centres. *International Journal of Cardiology* [Internet]. 2020 Dec 1; Available from: <http://www.sciencedirect.com/science/article/pii/S0167527320341541>
6. Stout KK, Daniels CJ, Aboulhosn JA, Bonzart B, Broberg CS, Colman JM, et al. 2018 AHA/ACC Guideline for the Management of Adults With Congenital Heart Disease: Executive Summary: A Report of the American College of Cardiology/American Heart Association Task Force on Clinical Practice Guidelines. *J Am Coll Cardiol*. 2019 02;73(12):1494–563.
7. Baumgartner H, De Backer J, Fabu-Narayan SV, Budts W, Chessa M, Diller G-P, et al. 2020 ESC Guidelines for the management of adult congenital heart disease. *European Heart Journal*. 2020 Aug 29;ehaa554.
8. Hilderson D, Saidi AS, Vin Deyk K, Verstappen 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 Aug 1;30(6):786–93.
9. Mackie AS, Rempel GR, Kovacs AH, Kaufman M, Rankin KN, Jelen A, et al. Transition Intervention for Adolescents With Congenital Heart Disease. *Journal of the American College of Cardiology*. 2018 Apr 24;71(16):1768–77.
10. Skogby S, Moons P, Johansson B, Sunnegårdh J, Christersson C, Nagy E, et al. Outpatient volumes and medical staffing resources as predictors for continuity of follow-up care during transfer of adolescents with congenital heart disease. *International Journal of Cardiology*. 2020 Jul 1;310:51–7.

Figure: Outline of the transition process

Based on service standards and specifications in England for the transition from paediatric to adult CHD services (available from: <https://www.england.nhs.uk/commissioning/spec-services/npc-crg/group-e/e05/>). ACHD: adult congenital heart disease; ACP: advance care planning; CHD: congenital heart disease; CNS: clinical nurse specialist; QoL: quality of life.