

Transition Intervention for Adolescents With Congenital Heart Disease



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ABSTRACT

BACKGROUND There is little evidence regarding the efficacy of interventions to prepare adolescents with congenital heart disease (CHD) to enter adult care.

OBJECTIVES The goal of this study was to evaluate the impact of a nurse-led transition intervention on lapses between pediatric and adult care.

METHODS A cluster randomized clinical trial was conducted of a nurse-led transition intervention for 16- to 17-year-olds with moderate or complex CHD versus usual care. The intervention group received two 1-h individualized sessions targeting CHD education and self-management skills. The primary outcome was excess time to adult CHD care, defined as the interval between the final pediatric and first adult cardiology appointments, minus the recommended time interval, analyzed by using Cox proportional hazards regression accounting for clustering. Secondary outcomes included scores on the MyHeart CHD knowledge survey and the Transition Readiness Assessment Questionnaire.

RESULTS A total of 121 participants were randomized to receive the intervention (n = 58) or usual care (n = 63). At the recommended time of first adult appointment (excess time = 0), intervention participants were 1.8 times more likely to have their appointment within 1 month (95% confidence interval: 1.1 to 2.9; Cox regression, p = 0.018). This hazard increased with time; at an excess time of 6 months, intervention participants were 3.0 times more likely to have an appointment within 1 month (95% confidence interval: 1.1 to 8.3). The intervention group had higher scores at 1, 6, 12, and 18 months on the MyHeart knowledge survey (mixed models, p < 0.001) and the Transition Readiness Assessment Questionnaire self-management index (mixed models, p = 0.032).

CONCLUSIONS A nurse-led intervention reduced the likelihood of a delay in adult CHD care and improved CHD knowledge and self-management skills. (Congenital Heart Adolescents Participating in Transition Evaluation Research [CHAPTER 2]; NCT01723332) (J Am Coll Cardiol 2018;71:1768-77) © 2018 by the American College of Cardiology Foundation.

More than 90% of children with congenital heart disease (CHD) in the current era reach adulthood (1), and the population of adolescents and young adults with CHD is growing exponentially (2). However, this emerging “survivor” population has complex needs. Unfortunately, between 21% and 76% of adolescents and young adults have a lapse in cardiology care (3-9). Loss to follow-up is an important challenge, as lapses in adult CHD care may predispose patients to delayed recognition



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of new cardiac problems (4,7,10). Yeung et al. (4) reported that a lapse in care of ≥ 2 years since leaving a pediatric cardiac program was associated with a 3-fold need for catheter or surgical intervention within 6 months of obtaining adult CHD care. However, the clinically meaningful threshold duration of a gap in care is unknown and may vary among subtypes of CHD.

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Transition from pediatric to adult health care is defined as “the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems” (11). Few data are available on to how to facilitate transition; only a single study of patients with CHD met criteria for entry in a recent Cochrane systematic review of transition interventions for adolescents, and this study did not assess timeliness of the first adult cardiology appointment (12). We therefore sought to evaluate the impact of a nurse-led transition intervention on lapses in care. We hypothesized that a transition intervention in combination with usual care would result in more timely first adult CHD clinic attendance compared with usual care alone. Secondary aims of the study were to describe the following: 1) change in participants’ knowledge of their CHD; 2) change in self-management and self-advocacy skills using validated instruments (13,14); and 3) incidence of cardiac procedures post-enrollment.

METHODS

The CHAPTER 2 (Congenital Heart Adolescents Participating in Transition Evaluation Research) study was a cluster randomized clinical trial using 2 parallel groups of adolescents attending outpatient clinics in 1 of 2 tertiary care pediatric cardiology programs in Canada. Institutional review board approval was obtained at each site. Written informed consent was obtained from participants and, if required, from their parent or guardian. The details of the methods and study design have been described previously (15). Eligible patients were 16 to 17 years old with moderate or complex CHD (16) who had not yet been transferred to adult care. We excluded patients with less than a grade 6 level of reading or comprehension, based on parent report, and those with a heart transplant.

Patients were assigned to clusters based on week of attendance in the cardiology clinic. Weeks were randomly assigned to “intervention” or “usual care” by a biostatistician. A 1:1 ratio of intervention:usual

care was used until midway through enrollment, after which the enrollment ratio was changed to a ratio of 1.5 intervention weeks:1 usual care week due to lower enrollment during intervention weeks. Randomization was stratified according to site. Permuted blocks of 2, 4, and 6 were used for 1:1 randomization; this method was changed to blocks of 5 and 10 when randomization was changed to 1.5:1 midway through enrollment.

The transition intervention consisted of 2 nurse-led 1-on-1 sessions. Parents were purposefully not present to promote the independent self-management of the transitioning youth. The first session was held in person on the day of a cardiology clinic appointment. The second session was held 2 months later, either in person or by teleconference or Skype for participants living far from the hospital. Details of the intervention have been published (15) and included 2 sessions; a brief description is given here.

Session 1 involved the creation of a MyHealth passport (17). This passport included review of the participant’s CHD anatomy, previous cardiac interventions, and name, dose, and rationale of cardiac medications; discussion of potential future cardiac complications; review of the names and location of local adult CHD cardiologists; introduction to relevant youth-friendly health care websites; discussion of 3 third-person scenarios (alcohol, smoking/street drugs, and sexuality/contraception); an introductory visit to the adult CHD clinic; and the setting of 1 education-related goal.

Session 2 included review of the education-related goal; discussion of 6 short videos illustrating young adults with poor versus strong communication skills with health care providers; viewing and discussion of a video titled “Talking With Your Doctor” (18); role-play of 2 standardized health care scenarios; discussion of effective goal-setting; review (and take home) of the booklet “When You’re 18” (19); and review of the “Health Care Transitions” website (20). Both sessions were followed by text message or e-mail interaction between the study nurse and participant within 7 days. Nurses documented the completion of each element of the intervention after each session. Intervention fidelity and quality assurance are described in the published protocol (15).

The usual care group did not receive the same educational materials as the intervention group. No transition program was formally in place at either site during the study period. At both sites, pertinent medical records were sent to adult CHD providers at the time of transfer. Both adult CHD clinics sent a

ABBREVIATIONS AND ACRONYMS

CHD = congenital heart disease

TRAQ = Transition Readiness
Assessment Questionnaire

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