Cardiology in the Young

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Differences in perceptions of transition readiness between parents and teens with congenital heart disease: do parents and teens agree?

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Abstract

Background: Amongst patients with CHD, the time of transition to adulthood is associated with lapses in care leading to significant morbidity. The purpose of this study was to identify differences in perceptions between parents and teens in regard to transition readiness. *Methods:* Responses were collected from 175 teen–parent pairs via the validated CHD Transition Readiness survey and an information request checklist. The survey was distributed via an electronic tablet at a routine clinic visit. *Results:* Parents reported a perceived knowledge gap of 29.2% (the percentage of survey items in which a parent believes their teen does not know), compared to teens self-reporting an average of 25.9% of survey items in which they feel deficient ($p = 0.01$). Agreement was lowest for long-term medical needs, physical activities allowed, insurance, and education. In regard to self-management behaviours, agreement between parent and teen was slight to moderate (weighted κ statistic = 0.18 to 0.51). For self-efficacy, agreement ranged from slight to fair (weighted $\kappa = 0.16$ to 0.28). Teens were more likely to request information than their parents (79% versus 65% requesting at least one item) particularly in regard to pregnancy/contraception and insurance. *Conclusion:* Parents and teens differ in several key perceptions regarding knowledge, behaviours, and feelings related to the management of heart disease. Specifically, parents perceive a higher knowledge deficit, teens perceive higher self-efficacy, and parents and teens agree that self-management is low.

There are an estimated 1 million children and 1.4 million adults living with CHD as of 2010,[1] with the age group of 13–17 years old representing the highest relative growth in prevalence.[2] It is anticipated that approximately 85% of CHD patients will survive to adulthood and the majority will require lifelong specialised CHD care.[3] The period of transition to adulthood, considered to be age greater than 17 years, is associated with lapses in care and patient misperceptions of medical needs, leading to unplanned hospitalisations, patient morbidity, and increased healthcare costs.[4–6] For teens with CHD, transfer of medical care to a qualified adult provider plays a key role in the complex psychosocial, cultural, and medical transition to a healthy and successful adult life. As noted in the American College of Cardiology/American Heart Association consensus statement in 2011, optimal transition requires a therapeutic alliance between patients, healthcare providers, and parents/caregivers, starting as early as at the age of 12.[7] In a consensus statement, the Society of Adolescent Medicine stated that "Many adolescents with chronic conditions are at higher risk than their peers for unnecessary dependency [. . .] A successful transition to adult health care may help prevent this by enhancing autonomy, increasing a sense of personal responsibility and facilitating self-reliance".[8] It is our hope that by identifying discrepancies in understanding between parents and teens, we can optimise patient encounters towards a healthy and successful transition to adulthood. A previously published study from this multicentre sample has shown that greater agreement between teen and parental perception of a teen's knowledge was associated with a greater increase in patient knowledge and self-efficacy.[9] The purpose of this study was to further characterise the specific gaps and differences in perceptions between patients with CHD and their parents in regard to transition readiness. These perceptions can influence patient behaviours, and may be instrumental in shaping transition-related interventions, a growing area of study.[10]

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Methods

As part of a multicentre study to evaluate transition readiness in teens/young adults with heart disease, responses were collected via electronic tablet in cardiology clinics from patients and one parent of each patient aged 13–18 years.[9] This study was approved by the Institutional Review Board at each site and informed consent was obtained from the study patients. Patients were recruited via convenience sample based on an existing diagnosis of heart disease and the reason for clinic visit was the routine follow-up. Patients were excluded if they were being evaluated for an acute issue, or if unable to complete the survey due to cognitive impairment. Eligible patients completed two questionnaires: the CHD Transition Readiness Assessment and an information request checklist. A parallel survey was distributed to one parent/caregiver for each patient, with identical survey items, but alternatively phrased to address the parent's perception of their child's knowledge, behaviour, and self-efficacy. Survey items regarding pregnancy and contraception were only queried to female respondents, and survey items regarding medications were only available after a respondent indicated they were taking at least one cardiac medication. Data were automatically downloaded for analysis using Research Electronic Data Capture (REDCap) software.[11]

The CHD Transition Readiness Assessment is a previously validated and reliable survey tool developed specifically for teens and young adults with CHD during the period of transition to adulthood.[12] The CHD Transition Readiness Assessment is comprised of three primary components: perceived knowledge; self-management; and self-efficacy. Amongst these three domains, the assessment captures a patient's knowledge, behaviours, and feelings, respectively. This is intended to form a complete picture of their readiness for transition to adulthood.

Perceived knowledge deficit is scored as the percentage of questions in which the respondent either did not know or was not sure of the information queried.[12] Parent responses reflect the parent's perception of their teen's knowledge, not their own knowledge. Reliability of these responses compared to actual knowledge has been evaluated as 86–90% during the validation of the Transition Readiness Assessment.[12] A higher knowledge deficit percentage corresponds to a more significant deficiency in knowledge (not a higher degree of transition readiness).

Self-management behaviours have been previously described as the patient's autonomy taking and refilling medications, contacting the medical team, making appointments, etc.[13] Self-management responses ranged from “almost always” to “never” in regard to frequency of patient behaviours.

Self-management is primarily related to *self-efficacy*, a person's belief about his or her ability and capacity to execute those behaviours.[12] Self-efficacy responses ranged from “very easy” to “very hard” in regard to a patient's perceived ability to execute these behaviours. Both self-management and self-efficacy, using the 5-point Likert scale data, were linearly transformed to a 0–100-point scale with higher scores indicating greater self-management and self-efficacy.

The request for information checklist asks the respondent if they have any interest in information on specific topics addressed in the Transition Readiness Assessment, along with the preferred source of information. Teens and parents received the same checklist, and the parental version was intended to reflect information that each parent desired (as opposed to what they believed their teen desired). The information request checklist was distributed via paper copy, not an electronic tablet.

Statistical analysis

Data are reported as frequency (%) for categorical variables and mean ± standard deviation or median with interquartile range for continuous variables. The overall transition readiness scores in perceived knowledge deficit, self-management, and self-efficacy were compared between parents and teens using a paired t-test. For knowledge deficit scores, Cohen's (unweighted) κ statistic was used to examine agreement between responses of teens and parents, with a value approaching 0 representing a higher degree of disagreement, while a value approaching 1 represents agreement.[14] Cohen suggests values ≤ 0 as indicating no agreement and 0.01–0.20 as none to slight, 0.21–0.40 as fair, 0.41–0.60 as moderate, 0.61–0.80 as substantial, and 0.81–1.00 as almost perfect agreement.[14] For self-efficacy and self-management, agreement on the responses for each individual survey item between teens and parents was evaluated using weighted Cohen's κ statistic, to account for 5-point ordinal Likert scale. The weighted κ statistic (as opposed to unweighted κ statistic) is calculated using a predefined table of weights measuring the degree of disagreement between two raters on the 5-point Likert scale. For example, a response of “almost always” compared to “often” carries less weight than “almost always” compared to “almost never”. Similar to the unweighted κ statistic, a value approaching 0 (or a negative value) indicates disagreement, while a value approaching 1 indicates agreement. Information request checklist items were also compared between teens and parents using McNemar's test. All analyses were performed using SAS version 9.4 (SAS Institute, Cary, NC, United States of America), with a statistical significance level of 0.05 using two-sided tests.

Results

Data were collected from 175 patient–parent pairs who participated in a larger study of transition readiness in teens and young adults previously reported.[9] Response rate amongst patients to whom the survey was offered was 91%. Patient characteristics are summarised in Table 1. Median patient age was 15.7 years. The patient cohort included in the analysis was 32.6% female, 88.0% Caucasian, and 53.7% were taking at least one cardiac medication. The cohort included a variety of structural heart lesions, including over one-third of respondents meeting criteria for great complexity as defined by the 32nd Bethesda Conference.[3] Eighty-five percent had previously undergone surgical intervention.

Parents perceived a higher knowledge deficit in their teens, as compared to teens' own self-perception of their knowledge. Pooled results amongst parents showed 29.2% of queried items in which they believed their teen did not know the answer, compared to 25.9% of teens themselves responding they did not know ($p = 0.01$). Across all knowledge items, agreement between parent and teen was moderate at best (κ range: −0.07–0.55), (Table 2). In regard to specific areas of perceived knowledge deficit, agreement between parents and teens was stronger in regard to the name of their heart condition/surgery ($\kappa = 0.41$), the purpose of their medicines ($\kappa = 0.42$), and the potential harm of medications during pregnancy ($\kappa = 0.55$). Agreement was weakest in terms of what exercise or sports activities were allowed ($\kappa = 0.10$), the need for lifelong cardiology follow-up ($\kappa = 0.10$), how to get health insurance ($\kappa = -0.07$), and ability to attend college ($\kappa = -0.02$).

With respect to self-management, scores were similarly low between teens and parents (mean 41.0 ± 15.8 for teens versus 39.3 ± 15.2 for parents, $p = 0.27$). In regard to individual behaviours, agreement was slight to moderate, with weighted κ statistic

Table 1. Patient and clinical characteristics in patients <18 years of age with heart disease (n = 175)

Median age, years (interquartile range)	15.7 (14.6–17.0)
Female sex	57 (32.6)
Caucasian race	154 (88.0)
Taking any cardiac medication	94 (53.7)
Diagnosis	
Single ventricle	33 (18.9)
Other complex	14 (8.0)
Left heart lesions, operated	21 (12.0)
Tetralogy of Fallot	22 (12.6)
Transposition of the great arteries	14 (8.0)
Heart transplant	4 (2.3)
Other (VSD, right heart lesions, aortic coarctation, etc.)	52 (29.7)
Bicuspid aortic valve	15 (8.6)
Surgical intervention	148 (84.6)

Data are presented as n (%) unless otherwise indicated

Table 2. Agreement between patients' and parents' perceived knowledge in patients < 18 years of age with heart disease (n = 175)

Question	κ**
1. Do you* know the name of your heart condition/surgery?	0.41
2a. Do you know the name of your heart medication? (n = 94)	0.17
2b. Do you know what the medicines are for? (n = 94)	0.42
2c. Do you know what could happen if you stopped taking your medicines? (n = 94)	0.20
2 d. Do you know how to refill your medication prescriptions? (n = 94)	0.46
3. Do you know what symptoms or problems your doctor needs to know about?	0.28
4. Do you know how to contact your doctor?	0.26
5. Do you know how often you need to see a heart doctor?	0.18
6. Do you know whether or not you will need to see a heart doctor for the rest of life?	0.10
7. Do you know whether or not you need an antibiotic medicine when you go to the dentist?	0.32
8. Do you know what exercises or sports activities you can and cannot do because of your heart condition?	0.10
9. Do you know how to get health insurance when you are not covered by your parents' plan?	−0.07
10. Do you know whether or not your heart condition could affect your ability to get pregnant? (n = 57)	0.37
11. Do you know whether or not your heart condition could get worse if you got pregnant? (n = 57)	0.36
12. Do you know whether or not any medicines could be harmful to an unborn baby if you became pregnant? (n = 57)	0.55
13. Do you know what someone with a heart condition like yours can do to protect herself from unplanned pregnancy? (n = 57)	0.25
14. Do you think the following statements are true or false?	
a. Because of my heart condition, I can't go to college	−0.02
b. Because of my heart condition, I can't get a job	0.49
c. Because of my heart condition, I can't have a certain job	0.32
d. Because of my heart condition, I can't have kids	0.36

*Questions in parental survey alternatively phrased "Does your teen . . . "

**Cohen's κ statistic was calculated. Cohen suggests values ≤ 0 as indicating no agreement and 0.01–0.20 as none to slight, 0.21–0.40 as fair, 0.41–0.60 as moderate, 0.61–0.80 as substantial, and 0.81–1.00 as almost perfect agreement

ranging from 0.18 to 0.51 (Table 3). Agreement was lowest for teen's understanding of what doctors told them with parents tending to overestimate their teen's understanding (with 80.6% of parents reporting their teen "often" or "almost always" understanding their doctor compared to 70.3% of teens, weighted κ = 0.18). There was also discordance between parental and teen reports in regard to the patient independently making his or her own appointments (weighted κ = 0.29), but there was a trend towards "never" and "almost never" for both groups (92% of teens reporting "never" or "almost never" compared to 96% of parents). Agreement was highest in regard to teens needing reminders to take medications and how often teens forget to take their medications (weighted κ = 0.43 and 0.44, respectively).

Teens scored significantly higher in overall self-efficacy as compared to their parents' perceptions (mean 68.2 ± 18.3 for teens versus 58.6 ± 21.1 for parents, $p < .0001$). Teens had a higher frequency of responding "very easy" or "somewhat easy" in all self-efficacy items, while parents more frequently responded "very hard" or "somewhat hard", and overall agreement ranged from slight to fair (weighted κ range of 0.16–0.28, Table 3).

Results from the request for information checklist are presented in Table 4. The checklist was available from 123 (70.3%) parents compared to 173 patients (98.9%). Patients were more likely to request at least one piece of information as compared to their parents (78.6% versus 65%, $p = 0.06$). Teens more frequently requested information than their parents related to how to contact their heart doctor (35.3% of teens compared to 10.6% of parents, $p < .0001$), health insurance needs (33.5% versus 13%, $p = 0.001$), pregnancy/pregnancy prevention (42.9% of female respondents versus 16.7% of corresponding parents, $p = 0.03$), and how to communicate with the healthcare team (22.5% versus 8.1%, $p < .0001$).

Discussion

In this study, we have identified significant gaps in perception between teens with CHD and their parents regarding critical factors in readiness for teens to transition to adulthood and towards independence in medical care. Prior studies have observed that young adults with CHD tend to remain dependent on their parents longer than their healthy peers.[15,16] Decreased communication between parents and teens may be a contributing factor to the lapses in care observed in the transitional age group.[5] For all of these reasons, it is important to characterise any transition-related misperceptions between parents and their children starting in the early teens, which in turn enables providers to proactively address these issues. Our study shows that the overall agreement between parents and teens was poor to fair, and the findings encountered here can guide us towards more effective patient and parent encounters.

In general, parents perceived a greater knowledge deficit in their teens than teens self-reported. Agreement was lowest for many

Table 3. Frequency and percentage of responses for self-management and self-efficacy in patients < 18 years with heart disease and their parents (n = 175)

Self-management	Never	Almost never	Sometimes	Often	Almost always	Incomplete	κ**
1. How often did you* understand what your doctor told you?							
Patient	2 (1.1)	2 (1.1)	47 (26.9)	66 (37.7)	57 (32.6)	1 (0.6)	0.18
Parent	1 (0.6)	1 (0.6)	31 (17.7)	66 (37.7)	75 (42.9)	1 (0.6)	
2. How often did you use the Internet, books, or other guides to find out more about your heart?							
Patient	41 (23.4)	55 (31.4)	49 (28.0)	21 (12.0)	7 (4.0)	2 (1.1)	0.22
Parent	47 (26.9)	55 (31.4)	50 (28.6)	14 (8.0)	8 (4.6)	1 (0.6)	
3. How often did you take your medicines on your own? (n = 94)							
Patient	2 (2.1)	6 (6.4)	14 (14.9)	24 (25.5)	47 (50.0)	1 (1.1)	0.51
Parent	4 (4.3)	5 (5.3)	17 (18.1)	23 (24.5)	42 (44.7)	3 (3.2)	
4. How often did you ask your doctor or nurse questions about your heart, medicines, or medical care?							
Patient	16 (9.1)	48 (27.4)	73 (41.7)	27 (15.4)	10 (5.7)	1 (0.6)	0.22
Parent	26 (14.9)	50 (28.6)	66 (37.7)	19 (10.9)	12 (6.9)	2 (1.1)	
5. How often did you make your own appointments?							
Patient	140 (80.0)	21 (12.0)	6 (3.4)	3 (1.7)	4 (2.3)	1 (0.6)	0.29
Parent	164 (93.7)	4 (2.3)	3 (1.7)	1 (0.6)	1 (0.6)	2 (1.1)	
6. How often did you need someone to remind you to take your medicines? (n = 94)							
Patient	6 (6.4)	16 (17.0)	35 (37.2)	23 (24.5)	13 (13.8)	1 (1.1)	0.43
Parent	13 (13.8)	20 (21.3)	32 (34.0)	16 (17.0)	10 (10.6)	3 (3.2)	
7. How often did you forget to take your medicines? (n = 94)							
Patient	2 (2.1)	4 (4.3)	36 (38.3)	40 (42.6)	11 (11.7)	1 (1.1)	0.44
Parent	1 (1.1)	10 (10.6)	34 (36.2)	37 (39.4)	9 (9.6)	3 (3.2)	

Self-efficacy	Very hard	Somewhat hard	Neither hard nor easy	Somewhat easy	Very easy	Incomplete	κ
1. How easy or hard is it for you* to talk to others (friends, family, etc.) about your condition?							
Patient	3 (1.7)	14 (8.0)	29 (16.6)	45 (25.7)	83 (47.4)	1 (0.6)	0.21
Parent	5 (2.9)	21 (12.0)	42 (24.0)	50 (28.6)	54 (30.9)	3 (1.7)	
2. How easy or hard is it for you to talk to your doctor or nurse?							
Patient	2 (1.1)	8 (4.6)	23 (13.1)	51 (29.1)	89 (50.9)	2 (1.1)	0.28
Parent	2 (1.1)	18 (10.3)	35 (20.0)	46 (26.3)	69 (39.4)	5 (2.9)	
3. How easy or hard is it for you to make a plan with your doctor to care for your health?							
Patient	8 (4.6)	17 (9.7)	61 (34.9)	49 (28.0)	38 (21.7)	2 (1.1)	0.16
Parent	12 (6.9)	33 (18.9)	51 (29.1)	39 (22.3)	36 (20.6)	4 (2.3)	
4. How easy or hard is it for you to call your doctor/nurse when you have a new problem or question?							
Patient	9 (5.1)	30 (17.1)	54 (30.9)	46 (26.3)	34 (19.4)	2 (1.1)	0.19
Parent	36 (20.6)	37 (21.1)	64 (36.6)	22 (12.6)	13 (7.4)	3 (1.7)	

(*Continued*)

Table 3. (*Continued*)

Self-efficacy	Very hard	Somewhat hard	Neither hard nor easy	Somewhat easy	Very easy	Incomplete	κ
5. How easy or hard is it for you to see your doctor by yourself?							
Patient	36 (20.6)	45 (25.7)	45 (25.7)	22 (12.6)	25 (14.3)	2 (1.1)	0.16
Parent	56 (32.0)	37 (21.1)	42 (24.0)	16 (9.1)	20 (11.4)	4 (2.3)	
6. How easy or hard is it for you to take your medicines without being reminded? (n = 94)							
Patient	2 (2.1)	10 (10.6)	12 (12.8)	35 (37.2)	34 (36.2)	1 (1.1)	0.25
Parent	5 (5.3)	17 (18.1)	11 (11.7)	28 (29.8)	28 (29.8)	5 (5.3)	
7. How easy or hard is it for you to take care of yourself?							
Patient	2 (1.1)	6 (3.4)	13 (7.4)	62 (35.4)	91 (52.0)	1 (0.6)	0.20
Parent	2 (1.1)	20 (11.4)	24 (13.7)	60 (34.3)	66 (37.7)	3 (1.7)	

*Questions in parental survey alternatively phrased “your teen . . . ”

**Weighted κ statistic was calculated. Cohen suggests values ≤ 0 as indicating no agreement and 0.01–0.20 as none to slight, 0.21–0.40 as fair, 0.41–0.60 as moderate, 0.61–0.80 as substantial, and 0.81–1.00 as almost perfect agreement

Table 4. Knowledge-seeking behaviour in parents and patients <18 years of age with heart disease

	By patient	By parent	
	(n = 173)	(n = 123)	p-value*
Would you be interested in information/advice regarding any of the topics below?			
Your heart condition/surgery	88 (50.9)	47 (38.2)	0.21
Your medications	42 (24.3)	23 (18.7)	0.22
Symptoms to call for	64 (37.0)	39 (31.7)	0.19
How to contact heart doctor	61 (35.3)	13 (10.6)	<.0001
Future needs for follow-up visits	56 (32.4)	28 (22.8)	0.052
Antibiotics for dental work	24 (13.9)	21 (17.1)	0.24
Exercise or sports recommendations	56 (32.4)	32 (26.0)	0.37
Job or vocational counselling	22 (12.7)	14 (11.4)	0.41
Health insurance needs	58 (33.5)	16 (13.0)	0.001
Pregnancy/pregnancy prevention	24/56 (42.9)	6/36 (16.7)	0.03
How to communicate with the healthcare team	39 (22.5)	10 (8.1)	<.0001
Stress management	34 (19.7)	20 (16.3)	0.49
Community resources including counselling	8 (4.6)	7 (5.7)	0.76
Number(s) of items completed on the request for information checklist			
No item completed on the list	37 (21.4)	43 (35.0)	0.06
At least one item completed on the list	136 (78.6)	80 (65.0)	
Preferred method to receive info			
Face to face from healthcare team	92 (53.2)	66 (53.7)	0.27
Handouts/brochures	29 (16.8)	28 (22.8)	0.02
Internet/website	44 (25.4)	40 (32.5)	0.08
Parent (for teens)	38 (22.0)	N/A	N/A

Data are presented as n (%)

*p-value from McNemar’s test for comparison between patient and parent important non-clinical factors, including college plans, insurance, and exercise or athletic participation. In contrast, agreement was high for name of the heart condition and what the medications are for. This may suggest that clinicians and/or parents focus less on elements that impact a patient's education, vocation, activities, and other lifestyle factors. We observed only fair agreement between parent and teen with respect to family planning and pregnancy. Deng, et al observed that family planning and pregnancy counselling in patients with CHD most commonly occurred between ages 20 and 25 despite the patient opinion that ages 16–18 would be preferable.[17] This age distinction is often around the age when parents are less likely to attend a clinic appointment, further suggesting teens may not be granted the space to discuss their care with their provider privately. In regard to exercise and activities, prior studies have shown that patients with CHD have a tendency to refrain from healthy exercise despite no medical contraindications.[18] Our observed disagreement between parents and teens in physical activity-related survey items suggests a lack of parent/teen communication on the topic or varied interpretations regarding counselling by clinicians when counselling is not specific ("activity as tolerated" or "can limit self"). Finally, we observed a notable parent/teen disagreement in knowledge deficit in regard to insurance, which is unsurprising based on typical parent/teen responsibilities. Still, we observed that teens do request insurance information frequently while parents do not. Lapses in insurance in patients with CHD were previously commonplace, although improving recently.[19] Our data suggest that teens may possess some awareness of a long-term need to manage their own insurance. Some clinics specialising in adolescents with chronic disease are integrating insurance counsellors, vocational/educational support, and social work into their care model,[20–22] and future studies will be useful in their application to CHD subspecialty care. Also in regard to long-term planning, agreement was low between parents and teens on whether a patient will need to see a heart doctor for the rest of their life. A lack of awareness of follow-up needs has been linked with loss to follow-up.[23]

Agreement between parents and teens on self-management was higher than other survey domains, however, overall scores were low. For example, although parents and teens agree, both have observed that teens frequently forget, or need reminders to take their medications. The self-management survey item of least agreement shows that over one in four teens did not fully understand what their doctor told them, while parents did not seem to observe this, identifying a concerning gap in teen comprehension. This aligns with prior studies that show patient confidence tends to outweigh practical medical management skills, possibly related to parental hesitancy to shift greater responsibility to their children.[24,25] Our data support prior studies in children with cardiovascular disease demonstrating that observable behaviours tend to have more patient–parent concordance than non-observable behaviours (thoughts and feelings).[26,27]

While parents and teens agreed that self-management was deficient, parents tended to underestimate their teen's self-efficacy. For self-efficacy, agreement was highest regarding how easy or hard it is for teens to talk to their doctor or nurse, with responses weighted towards "very easy" or "somewhat easy". This is in contrast to self-management data, where two-thirds of teens reported "sometimes" or "almost never" asking questions to the medical team. Teens indicated that they feel comfortable discussing their condition, but data suggest they are not granted the space to do so. Providers may direct their conversation towards the parent, which in turn may lead to poor engagement by the patient. Furthermore, certain topics such as pregnancy/pregnancy prevention or stress management may be better suited for a private conversation with the patient/provider only,[28] and these topics were amongst the most commonly requested educational materials requested by teens, but not requested by their parents. This serves as a reminder that teen patients should be given the opportunity to ask questions to their provider without a parent present, which does not always happen during a clinical encounter. It will also prepare teens to eventually see their provider independently.

Patients were more likely to respond "often", whereas parents were more likely to respond "never" in regard to their teen's utilisation of supplemental materials including the Internet or books. In the information request checklist, teens were more likely to request additional educational materials than their parents. Approximately half preferred to receive medical information via a method other than face-to-face contact.[9] This suggests that teens may independently be researching their heart condition without their parent's knowledge, showing independence, initiative, and a desire to learn and advocate for their care. However, teens are at risk of encountering misinformation on their condition from the Internet or via social media unbeknownst to parents. Institution-sponsored web-based and app-based tools are currently in development, with the ultimate goal to provide accurate personalised educational materials for each patient.[29,30] The use of technology has been linked with a higher degree of self-management in teens with chronic conditions.[31] Applebaum and colleagues found a high proportion of teens felt comfortable communicating with the medical team via text message and expressed a desire for an online information-sharing platform.[32] Current sharing of protected health information via institutional EMR-based web platforms often prohibits teens from independent use without parental consent. The majority of Internet-based tools are targeted at older adults and parent caregivers,[33,34] although some promising adolescent-targeted websites are emerging that offer general CHD content, but not specific to the individual patient.[35,36] The items with the greatest disagreement between parents and teens on the information request checklist were in regard to contacting the medical team, and an EMR-integrated, adolescent-focused patient portal may be an effective intervention. If providers can engage parents to promote their child's independence via new technology, the findings reported in this study show that patients are eager to try to utilise it.

Of note, the Transition Readiness Assessment tool used in this study evaluates patient and parent perceptions of knowledge gaps, rather than a test of their actual knowledge. Prior studies have examined parent/teen knowledge, when Hsiao-Ling, et al in Taiwan found that higher parental disease knowledge corresponds with increased disease knowledge in teens.[37] Our findings support a study from Burstrom, et al who observed that teens perceive themselves as more prepared to take over responsibility for their health and to be transferred to adult care as compared to their parents.[38] Our data suggest that the teen and parent perception of disease knowledge is a distinct and likely an equally important driver of patient and parent behaviours.

Limitations of this study include the lack of data surrounding parental behaviours and parenting styles, along with a high degree of variability amongst providers in regard to counselling practices and resources offered to families, which certainly influence readiness for transition. Although the study was conducted at multiple centres, there still was a lack of racial diversity amongst patients, and parental demographics were not obtained. In future studies, a more diverse sample may help identify groups in most need of transition education, and could guide educational initiatives or programming. Additionally, our convenience sample is limited to patients attending clinic visits, and therefore no data were obtained on patients lost to follow-up, a critical and challenging population to study.

Overall, parents and teens differ in several key perceptions regarding knowledge and management of heart disease, including lifestyle implications of CHD. While, some degree of direct parental supervision may be necessary during the earlier teen years, especially regarding practical matters like medication adherence or appointment-making, parents need support in teaching their teens to take responsibility for their health needs. Providers and parents can work together to help foster independence in teens with CHD through earlier patient-centred clinical encounters, encouraging communication in the home, and attention to the teen's specific information needs and preferences.

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Conflicts of interest. None.

Ethical standards. All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee. Informed consent was obtained on all study participants.

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