Transition to adult health care for adolescents and young adults with congenital heart disease: Perspectives of the patient, parent and health care provider

Nadia A Clarizia BSc, Nita Chahal MN CNS-NP, Cedric Manlhiot BSc, Jennifer Kilburn MN,
Andrew N Redington MD, Brian W McCrindle MD MPH

NA Clarizia, N Chahal, C Manlhiot, J Kilburn, AN Redington, BW McCrindle. Transition to adult health care for adolescents and young adults with congenital heart disease: Perspectives of the patient, parent and health care provider. Can J Cardiol 2009;25(9):e317-e322.

BACKGROUND: Pediatric institutions play a large role in preparing young adults with congenital heart disease to transition to adult care.
OBJECTIVE: To determine the perspectives of patients, parents and providers on transition preparation.
METHODS: Patients aged nine to 18 years with congenital heart defects and their respective parent(s) participated in semistructured interviews. Health care providers completed a self-administered survey.
RESULTS: A total of 23 patients, 22 parents and 45 health care providers were enrolled in the study. Only 36% of patients demonstrated a clear understanding of transition and its implications for their cardiac care. Parents were extensively involved in care activities, with 95% accompanying their child to visits at the clinic, 68% staying with their child for the entire visit and 45% administering their medication. Children more knowledgeable about their diagnosis demonstrated a better understanding about their transition to adult care (100% versus 7%, respectively; P<0.01) and were more likely to communicate directly with their providers than those who were less or not knowledgeable (88% versus 33%, respectively; P=0.03). Nurses were more likely than physicians to view increased parental involvement in care activities as a barrier to transition preparation (37% versus 5%, respectively; P=0.02).
CONCLUSIONS: A lack of clear role expectations indicates a need for the pediatric health care setting to adapt appropriately to address the shifting needs of adolescent and young adult patients and their families. A formalized approach to transition preparation for adolescents with congenital heart disease needs to emphasize comprehensive education. A delegation of explicit responsibilities and the clear definition of roles for parents, providers and patients are necessary to provide young adults with the resources and support necessary to achieve a successful transition to adult care.

Key Words: *Congenital heart disease; Education; Health care delivery; Pediatrics*

La transition des adolescents et des jeunes adultes ayant une cardiopathie congénitale vers les soins pour adultes : Les points de vue du patient, des parents et des dispensateurs de soins

HISTORIQUE : Les établissements pédiatriques jouent un rôle important dans la préparation des jeunes adultes ayant une cardiopathie congénitale à la transition aux soins pour adultes.
OBJECTIF : Déterminer les points de vue des patients, des parents et des dispensateurs de soins sur la préparation à la transition.
MÉTHODOLOGIE : Les patients de neuf à 18 ans ayant une cardiopathie congénitale et leur(s) parent(s) respectif(s) ont participé à des entrevues semi-structurées. Les dispensateurs de soins ont rempli un sondage autoadministré.
RÉSULTATS : Au total, 23 patients, 22 parents et 45 dispensateurs de soins ont participé à l'étude. Seulement 36 % des patients comprenaient clairement la transition et ses répercussions sur leurs soins cardiaques. Les parents participaient abondamment aux activités reliées aux soins, 95 % d'entre eux accompagnant leur enfant aux visites à la clinique, 68 % demeurant avec leur enfant pendant toute la visite et 45 % leur administrant leurs médicaments. Les enfants mieux informés de leur diagnostic comprenaient mieux la transition aux soins aux adultes (100 % par rapport à 7 %, respectivement, P<0,01) et étaient plus susceptibles de communiquer directement avec leur dispensateur que ceux qui étaient moins informés ou qui ne l'étaient pas du tout (88 % par rapport à 33 %, respectivement; P=0,03). Les infirmières étaient plus susceptibles que les médecins de percevoir la participation accrue des parents aux soins comme un obstacle à la préparation à la transition (37 % par rapport à 5 %, respectivement; P=0,02).
CONCLUSIONS : L'absence d'attentes claires quant aux rôles démontre la nécessité que le milieu de la santé pédiatrique s'adapte convenablement aux besoins évolutifs des patients adolescents et jeunes adultes ainsi qu'à ceux de leur famille. Une démarche officielle de préparation à la transition pour les adolescents ayant une cardiopathie congénitale doit s'attarder sur une formation complète. Il est essentiel de déléguer explicitement les responsabilités et de définir clairement les rôles des parents, des dispensateurs et des patients pour que les jeunes adultes disposent des ressources et du soutien nécessaires pour vivre une transition réussie vers les soins pour adultes.

Approximately 85% of children born with congenital heart disease (CHD) survive into adulthood (1,2). This increasing phenomenon has created a need for transition, which is defined as the "purposeful and planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems" (3). Ensuring continuity of quality care is the primary goal of transition. It is crucial that young adults with CHD are made aware of the need for regular medical follow-up because they are at high risk for complications later in adulthood (4-11). A previous study (12) found that only 47% of CHD patients transition to adult care successfully.

Preparing young adults for the change in health care setting is vital to a successful transition to adult care (3,13,14). It is appropriate to consider the role of the family, particularly parents, because they serve as integral members of their child's health care team (15). Educating patients about their diagnosis, management and preventative health measures – both general and diagnosis-specific (12,13,16) – and encouraging independence and self-advocacy in the adolescent patient

Division of Cardiology, Department of Pediatrics, University of Toronto, The Labatt Family Heart Centre, The Hospital for Sick Children, Toronto, Ontario
Correspondence: Dr Brian W McCrindle, The Hospital for Sick Children, 555 University Avenue, Toronto, Ontario M5G 1X8.
Telephone 416-813-7610, fax 416-813-7547, e-mail brian.mccrindle@sickkids.ca
Received for publication August 15, 2007. Accepted April 6, 2008

TABLE 1
Patient characteristics (n=23)*

Characteristic	n (%)
Girls	9 (39)
Patient age, years	
9 to 12	7 (30)
13 to 16	11 (48)
17 to 18	5 (22)
Diagnosis	
Tetralogy of Fallot	5 (22)
Ventricular/atrioventricular septal defect	9 (38)
Aortic valve stenosis	2 (9)
Other congenital heart malformation	5 (22)
Congenital syndromes	2 (9)
Age at presentation to pediatric institution, years	
Birth to 4	12 (52)
5 to 9	4 (17)
10 to 12	2 (9)
≥13	5 (22)
Clinic visit frequency	
Every 1 to 5 months	4/22 (18)
Every 6 to 11 months	6/22 (27)
Every 1 to 2 years	7/22 (32)
Every 3 to 5 years	5/22 (23)
Number of previous surgeries	
None	7/22 (32)
1	8/22 (36)
2	3/22 (14)
≥3	4/22 (18)

**Unless otherwise indicated*

(14,15) reinforces the importance of ongoing care. Referral to adult practitioners must be facilitated (12). Patients and providers need to be aware of the differences between adult and pediatric care (17,18), and institutional support from all members of the pediatric health care team must exist to support all aspects involved in preparation (16,19). Also requiring consideration is preparation for the patient's transition to adult life, addressing sexuality, family planning and employment. All of these issues need to be addressed systematically and comrehensively to ensure that adolescents with CHD are prepared to take complete responsibility for their health (20).

We examined the attitudes and opinions regarding transition and its necessary preparation from the perspectives of patients, their parents and health care providers in a pediatric cardiology outpatient clinic.

METHODS

Cohort description and data collection

A sample of consecutive patients and their respective parents who presented for regular follow-up in the pediatric cardiology outpatient clinic over a six-week period were asked to participate in the study. Those who showed interest were enrolled. Eligible patients had congenital heart defects and were between nine and 18 years of age at the time of the study. Patients with developmental delay or disability were excluded. No formal 'transition program' was in place at the time. Semistructured interviews were conducted by research staff with each patient and his or her parent(s) separately, whereby a set number of questions were asked of the respondent. However, the interview was presented as a discussion in which respondents were free to ask their own questions and discuss issues they felt were relevant. A self-administered survey was given to health care providers including pediatric cardiologists, nurses and allied health professionals (dieticians, social workers, occupational therapists and child-life specialists). The study was approved by the institutional research ethics board. The observational nature of the study precluded the need for individual consent; an explanatory letter was provided in lieu of a consent form and consent was inferred from participation.

Interviews

Interviews with the patient focused on how knowledgeable the patient was about his or her diagnosis, antibiotic prophylaxis and medications. Specific attention was given to the amount of discussion providers dedicated to smoking, alcohol consumption, sexuality and physical activity in relation to the patient's heart condition. The interview explored the patient's current knowledge about transition and what topics the patient wished to receive more information about at his or her routine clinic visits. A total of 14 questions were asked.

Interviews with parents focused on assessing their knowledge of and concerns about the transition process, and whether they perceived their child to be ready for transition. Information was obtained regarding the extent of involvement of the parent(s) in their child's care and what the parents believed about their roles and the roles of their child, nurses and physician in preparing their child for transition. A total of 17 questions were asked. The interview duration was between 15 min and 25 min.

Survey

The survey for health care providers examined the opinions and attitudes about the state of transition preparation in the outpatient clinic, what they perceived as barriers to successfully transitioning their patients, what they currently do to prepare them and what they felt was necessary to prepare their patients more effectively. The survey consisted of six questions.

Statistical analysis

Data are presented as means with SDs, medians with ranges, and frequencies as appropriate. Associations between the parents' and children's responses, as well as interprofessional differences in responses to the health care provider survey, were determined using Fisher's exact test, Student's *t* test with Sattertwaite correction if necessary and general linear models as appropriate. Univariate analysis was performed because the small sample size was not amenable to multivariable comparisons. All statistical analyses were performed using SAS Statistical Software version 9.1 (SAS Institute Inc, USA).

RESULTS

A total of 23 patients (nine girls [39%]), 22 of 23 parents and 45 of 134 health care providers participated in the study. All patients and parents who were asked to participate agreed, except for one parent who could not complete the interview because of time constraints. Patients recruited from the CHD clinic were between nine and 18 years of age at the time of the interview; nearly one-half (n=11 [48%]) were between 13 and 16 years of age. The diagnoses of patients and a summary of their medical care are detailed in Table 1. The health care provider survey was completed by 19 nurses, 21 pediatric cardiologists and five allied health care professionals.

Patient and parent responses to selected interview questions are shown in Table 2. While the majority of patients demonstrated at least a basic knowledge and comprehension of their heart conditions (n=17 [74%]), there was an evident gap of knowledge, with only 36% showing a clear understanding of the implications and changes associated with their future transition to adult care. A total of 43% of patients expressed a desire for more information about their heart condition.

Most parents (n=19 [86%]) were aware that their child would transition to adult care. Nearly one-half (n=9 [41%]) reported some concerns about transition and 50% felt that their child was ready for transition. Parents' involvement in their child's care was found to be extensive, with 95% of parents accompanying their child to medical appointments, 68% staying with them for the entire visit and 45% administering their medication. Parents were somewhat unclear about their role and the role of providers in preparing their child for transition, as demonstrated by the great variability in parents' responses.

TABLE 2
Patient and parent responses to semistructured interviews

Patient interview (n=23)*	n (%)
Do you know what the problem with your heart is? *Yes*	17 (74)
Describe the problem with your heart in your own words. *Accurate description*	16 (69)
Do you take antibiotics when you go to the dentist? *Yes*	17 (74)
Explain why you need to take antibiotics when you go to the dentist. *Accurate explanation*	11 (48)
What is the name of your heart doctor at SickKids? *Able to name*	18 (78)
Tell me the name of your [heart] medication. *Able to name*	4/6 (67)
Has a doctor or nurse discussed with you transition to an adult hospital? *Yes*	15/22 (68)
Has a doctor or nurse talked to you about:	
Heart healthy eating choices. *Yes*	10 (43)
Physical activity in relation to your heart problem. *Yes*	17 (74)
How taking drugs, alcohol or smoking could affect your heart problem. *Yes*	7 (30)
Pregnancy in relation to your heart condition. *Yes*	5/8 (63)
What is your understanding about who will look after your heart-related concerns after your 18th birthday? *Detailed and accurate answer*	8/22 (36)
Which of the following topics would you like to learn more from your heart doctor or nurse:	
About your heart problem. *Yes*	10 (43)
Medication related to your heart. *Yes*	7 (30)
Healthy eating. *Yes*	9 (39)
Physical activity. *Yes*	13 (57)
Vocation/employment. *Yes*	11 (48)
Managing personal emotions. *Yes*	9 (39)
Support groups for adolescents with heart conditions. *Yes*	5 (22)
Sexual health, contraception and pregnancy. *Yes*	6 (26)
Drugs/alcohol. *Yes*	8 (35)
Parent interview (n=22)*	
Are you aware that at the age of 18 your child will no longer be cared for at SickKids? *Yes*	19 (86)
Do you have any concerns about your child leaving SickKids care?	
General/undefined concerns	9 (41)
Child starting care with a new medical team	8 (36)
Child's ability to get similar treatment standards	6 (27)
Child's ability to have regular follow-up/appointments	8 (36)
Do you take part in administering medication? *Yes*	10 (45)
Do you accompany your child to medical appointments? *Yes*	21 (95)
Do you stay with your child for all parts of the visit? *Yes*	15 (68)
During discussions with physicians and nurses, who usually responds to questions, you or your child? *Child*	14 (64)
Do the physicians or nurses encourage your child to respond for themselves? *Yes*	22 (100)
What do you think your role is in preparing your child right now for transition to adult care?	
Managing their child's medical care (appointments)	5/21 (24)
Educating their child on his/her heart condition and care	11/21 (52)
Encouraging their child's independence	9/21 (43)
What do you feel should be the responsibility of the nurse and the doctor [in transition preparation]?	
Nurses – educate and support patient	12/20 (60)
Nurses – prepare referral documentation	5/20 (25)
Physicians – ensure proper, continuing care	13/20 (65)
Physicians – educate and support patient	7/20 (35)
Do you think these persons [physicians and nurses] are filling their roles? *Yes*	17/21 (81)
Do you think that when your child is 18 he or she will be ready to take complete responsibility for their health? *Yes*	11/20 (55)
What kind of support would you like from hospital staff so you can better help prepare your child for the transition to adult care?	
Education about heart conditions	9/20 (45)
Information about adult care	7/20 (35)
Referral to adult care	3/20 (15)

**Unless otherwise indicated. Patient and parent responses presented in italics. SickKids The Hospital for Sick Children (Toronto, Ontario)*

TABLE 3
Health care provider responses to transition survey (n=45)*

Respondents	n
Nurses (outpatient clinic)	12
Nurses (inpatient unit)	7
Staff cardiologists	13
Cardiology fellows	8
Social worker, dieticians, child life specialists, occupational therapists	5
Survey	**n (%)**
Currently, do you feel that adolescents in the cardiac program are adequately prepared for their transition from pediatric to adult care? *Yes*	9/29 (31)
From your experience, at what age do you feel a child/adolescent is ready to begin learning about the transition process?	
9–12 years old	7 (16)
13–16 years old	32 (72)
17–18 years old	6 (14)
From your experiences, which criteria would you identify as the greatest barriers for successful adolescent transition into adult care? (could choose more than 1 answer)	
Adolescent's limited understanding of his or her condition, medication, etc	31 (69)
Lack of self advocacy	35 (78)
Lack of structure in current transition program	31 (69)
Lack of time during clinic appointments to address all issues	25 (56)
Parental reluctance to transition	31 (69)
Lack of trust in adult health care providers	15 (33)

Identify ways in which you have been involved in preparing your patients at each clinic visit for adult health care services (could choose more than 1 answer):	Total (n=40), n (%)	Nurses (n=14), n (%)	Physicians (n=21), n (%)	P
Teaching about diagnosis/procedures	26 (65)	7 (50)	18 (86)	0.03
Teaching about medication and purpose	23 (58)	8 (57)	14 (67)	0.57
Reviewing current plan of care	27 (68)	9 (65)	16 (76)	0.45
Reviewing symptoms to watch for	27 (68)	8 (57)	19 (90)	0.03
Teaching about endocarditis	25 (63)	8 (57)	17 (81)	0.13
Seeing patient on their own	13 (33)	4 (29)	6 (29)	1.00
Discussion of future care	26 (65)	7 (50)	15 (71)	0.20

**Unless otherwise indicated. Responses presented in italics*

However, when asked, 17 (81%) parents felt that the institution was preparing their child for transition.

Responses to selected items of the survey for health care providers are shown in Table 3. Providers felt that, currently, children were not sufficiently prepared for transition (n=20 [69%]). The majority of providers thought that children should start learning about transition between 13 and 16 years of age (n=32 [72%]). Physicians were found to be more involved in teaching about diagnosis and symptoms than nurses (86% versus 50%, respectively, P=0.05; and 90% versus 57%, respectively, P=0.04).

Associations between parent and patient responses to interview questions are shown in Table 4. An association was observed among a child's knowledge, self-advocacy in the health care setting, and his or her understanding of the implications of transition. Children with more versus less or no knowledge about their heart condition were

TABLE 4
Associations between parent and patient responses to interview questions

Do you know what the problem with your heart is?	**Yes (n=17)**	**No (n=6)**	**P**
Presented to the pediatric hospital before 10 years of age	14/17 (82)	2/6 (33)	0.05
Patient – "Describe the problem with your heart." *Accurate description given*	14/17 (82)	2/6 (33)	0.05
Parent – "Who usually responds to doctors' and nurses' questions?" *Child*	14/16 (88)	2/6 (33)	0.03
Parent – "Do you think doctors and nurses are filling their roles [in transition preparation]?" *Yes*	15/16 (94)	2/5 (40)	0.03
What is your understanding about who will look after your heart-related concerns after your 18th birthday?	**Accurate answer (n=8)**	**Inaccurate answer (n=14)**	**P**
Less than 13 years old at interview	0/8 (0)	7/14 (50)	0.03
Patient – "Describe the problem with your heart." *Accurate description*	8/8 (100)	1/13 (7)	<0.01
Parent – "What do you feel is the responsibility of the doctor." *To encourage self-advocacy*	3/7 (43)	0/12 (0)	0.04
Parent – "What support would you like to better help prepare your child for transition?" *Information about adult experience and adult care*	5/7 (72)	2/12 (17)	0.02
What would you like to learn more from your heart doctor or nurse? *Heart problem*	**Mentioned (n=10)**	**Not mentioned (n=13)**	**P**
Patient – "Describe the problem with your heart" *Accurate description*	5/10 (50)	12/13 (92)	0.05
Parent – "Who usually respond to doctors' and nurses' questions?" *Child*	5/10 (50)	11/12 (92)	0.05
Parent – "Do you talk to your child about their heart problem?" *Never/rarely*	4/10 (40)	0/12 (0)	0.03
Parent – "What do you feel is your responsibility" *Educate and help understand*	2/9 (22)	9/12 (75)	0.03
How does this [transition] make you feel?	**Not/slightly concerned (n=15)**	**Somewhat/very concerned (n=7)**	**P***
Parent – "Do you talk to your child about their heart problem?" *Frequently*	2/15 (13)	5/7 (71)	0.02
Parent – "What part of your child's care do you take part in?" *Administer medication*	6/15 (40)	4/7 (57)	0.06
Parent – "Who usually responds to physicians' and nurses' questions?" *Child*	11/15 (73)	3/7 (43)	0.03
Parent – "What support would you like to better help prepare your child for transition?" *Education*	8/14 (57)	1/6 (17)	0.03
Patient – "What would you like to learn more from your heart doctor or nurse?" *About medications*	3/15 (20)	4/7 (57)	0.05
Do you think that when your child is 18 he or she will be ready to take complete responsibility for their health?	**No (n=9)**	**Yes (n=11)**	**P***
Male sex	4/9 (44)	9/11 (82)	0.03
Parent – "Who usually responds to physicians' and nurses' questions?" *Child only*	1/9 (11)	6/11 (55)	0.04
Parent – "Do you talk to your child about their heart problem?" *Appropriate situation only*	2/9 (22)	7/11 (64)	0.04
Parent – "What support would you like to better help prepare your child for transition?" *Education*	2/9 (22)	7/11 (64)	0.02
Parent – "How does this [transition] make you feel?" *Concerned/very concerned*	5/9 (56)	1/11 (9)	0.005

*Data presented as n/n (%). The frequency of answers by groups for dichotomous variables and parameter estimates (with standard estimate) for scales is presented. Responses are in italics. *Reported P-values are from linear regression models, data have been dichotomized for presentation*

more likely to respond to providers' questions themselves (88% versus 33%, respectively; P=0.03). They also demonstrated an understanding of the implications of transition to adult care (100% versus 7%, respectively; P<0.01). Children who reported needing more versus less or no information about their heart condition were more likely to let their parents answer providers' questions (50% versus 8%, respectively; P=0.05).

Parents who reported having concerns about transition were more likely than those without concerns to answer providers' questions for their child (57% versus 27%, respectively; P=0.03). They were also more likely to report not thinking that the institution's role was to educate their children about their heart condition and encourage their child to be self-advocating (83% versus 43%, respectively; P=0.03) but had children who were more likely to report needing more information about their care (57% versus 20%; P=0.05). In contrast, parents who reported that their children were ready to take responsibility for their care, versus those who did not, were more likely to report letting their child answer providers' questions for themselves (55% versus 11%, respectively; P=0.04) and report discussing their child's heart condition only in medically relevant situations (64% versus 22%, respectively; P=0.04), rather than making it a dominant topic in their child's life.

As shown in Table 5, providers who reported that the cardiac program was currently not adequately preparing children for transition felt that the lack of a formal transition program was an important problem (90%). Compared with physicians, nurses were more likely to see parental involvement in care activities as a significant obstacle to successful preparation for transition (37% versus 5%, respectively; P=0.02).

DISCUSSION

Currently, children born with CHD have a rate of survival and functional health status that was not experienced in the past. The need for their transition to adult care has posed numerous challenges for pediatric health care providers. By providing insight from the perspectives of key stakeholders in the transition process – patients, parents and providers – the present study identified areas of concern and provided an orientation for which to direct future endeavours in transition for the pediatric CHD clinic.

Patients who were more knowledgeable about their heart condition were more confident about their ability to care for themselves and tended to navigate the health care system independently from their parents. Parents who took responsibility for all or most of their child's care activities appeared to impede development of confidence and independence by not allowing their children the opportunity to take an active role in their own care. The pediatric cardiologists may be enabling this type of parental involvement because they do not feel as though parents are obstacles to transition preparation, while nurses reported that parents impede the process. Alternatively, the child may lack the confidence to be self-advocating about their health and thus, parents feel obligated to take over certain aspects of care. The delegation of explicit responsibilities and a clear definition of roles for each participant are needed.

Providing patients with complete and accurate information about their diagnosis and its implications for their physical, sexual, emotional and mental health translates into confidence in the health care setting (21). Patients who were able to explain their diagnosis in both lay and medical terms appeared to be more confident. They communicated

TABLE 5
Associations among responses to survey for health care providers

Currently do you feel that adolescents in the cardiac program are adequately prepared for their transition process from pediatric to adult care?	**Yes (n=9)**	**No (n=20)**	**P**
Which criteria would you identify as the greatest barriers for successful adolescent transition into adult care? *Lack of structure in the current transition program*	3/9 (33)	18/20 (90)	0.004
Which criteria would you identify as the greatest barriers for successful adolescent transition into adult care? *Lack of trust in adult health care providers*	6/9(67)	4/20 (20)	0.04
What are your suggestions for overcoming these barriers [to successful transition]? *Formal transition program*	1/9 (11)	11/20 (55)	0.05
At what age do you feel a child/adolescent is ready to begin learning about the transition process?	**Before 13 years of age (n=7)**	**13 years of age and older (n=38)**	**P**
Do you feel that adolescents in the cardiac program are adequately prepared for their transition from pediatric to adult care? *No, learn about it too early*	4/7 (57)	2/21 (10)	0.04
Identify ways in which you have been involved in preparing your patients for adult health care services. *Teach about diagnosis and procedures with patients*	0/7 (0)	14/33 (42)	0.04
Comparison of nurses and physicians	**Physicians**	**Nurses**	**P**
What are your suggestions for overcoming these barriers [to successful transition]? *Limit parental involvement*	1/21 (5)	7/19 (37)	0.02
Identify ways in which you have been involved in preparing your patients for adult health care services. *Teach about diagnosis and procedures with patients*	18/21 (86)	7/14 (50)	0.05
Identify ways in which you have been involved in preparing your patients for adult health care services. *Teach about symptoms requiring medical care*	19/21 (90)	8/14 (57)	0.04

Data presented as n/n (%). The frequency of answers by groups is presented. Responses are in italics

directly with providers instead of using their parents as a proxy, and were self-assured in their ability to take care of themselves. Patients who were unable to describe their diagnosis and its health implications did not exhibit this confidence, and often relied on their parents to communicate their needs to providers. There is a demonstrable need for consistent and thorough developmentally appropriate education for patients with CHD. Ideally, this education should begin as early as possible.

Parental involvement was found to influence a child's ability to take responsibility for his or her own health care. Parents who assumed responsibility for most or all aspects of their child's care had children who were unsure of their diagnosis and did not communicate directly with their providers. The child's parents were also less likely to support and encourage independence, and often took over aspects of care that would be appropriate for a young adult to do for him- or herself (eg, medication administration). In contrast, parents of children who were generally confident and knowledgeable about their child's diagnosis tended to encourage their child's independence in the health care setting by letting them see providers alone and encouraging them to take an active role in their care. This observation contradicts some of the literature that does not implicate parents as barriers to transition (20); however, each disease group has unique barriers to successful transition preparation. Increased condition complexity has been associated with more successful transition (12,22) and therefore, a disease-specific approach that recognizes these unique barriers is necessary when considering transition preparation for the young adult.

Physicians in pediatric specialties train intensively in a discipline that embraces parental involvement. They also view patients in the context of a family structure (18). The amount of parental involvement may be unduly influenced by the practice of family-centred care because physicians were less likely to view parents as barriers to successful transition preparation. Family-centred care encourages parents to take an active role in their child's care. However, at the time of transition, care in the pediatric setting must adapt to accommodate the presence of an additional adult (the patient), who needs to be treated independently of the family structure. While the literature advocates for a strong parent-provider relationship (17), a patient-provider relationship is also appropriate. A patient who is able to establish a relationship with his or her physician in the pediatric setting will have more confidence to do the same with a new adult provider. Both the pediatric physician and the patient need to strive for this. Devoting a portion of the visit to seeing the patient without his or her parents present is a gentle push that obliges the young adult to be a self-advocate of his or her health and also encourages the parent to begin playing a lesser role in his or her child's care. It is also an opportune time to teach about diagnoses and discuss the imperative of regular care.

Parents and providers have varying expectations as to what responsibilities should be undertaken by whom during transition preparation (23). There is no clear pattern that would suggest that roles are defined for parents, physicians, nurses and allied health professionals. The variation in responses highlights the need for explicit role assignments for each participant (19) to tend to all the preparation needs of transition. Once these roles are filled, expectations of the young adult can be defined and a comprehensive approach can be adopted for transition preparation. Such an approach, while focusing on a family's needs (22,24), would just as importantly focus on the individual patient's needs (13).

Limitations

The present study is limited by its sample because only eligible patients who had time to participate were enrolled. This excluded a number of eligible participants whose participation was unfeasible from a time perspective. In addition, the study is somewhat limited by its small sample size. However, the scope of the investigation has provided a relevant depiction of the needs of transitioning patients. By identifying critical areas for intervention by the pediatric institution, the present study has provided a starting point for transition preparation endeavours in the pediatric CHD clinic.

CONCLUSIONS

There is a demonstrated need for a formalized, systematic approach to transition preparation for adolescents with CHD, and providers in the pediatric setting must take responsibility of this task. Health care providers need to explicitly define their roles in preparing patients for transition. Special focus should be given to consistent, thorough and comprehensive patient education, mitigation and redefinition of the parent's role in the young adult's care, and agreement among health care providers to ensure that these goals are achieved. A concerted effort must be made to implement a formalized transition process as part of the regular routine of the outpatient clinic visit. This will ensure that young adults with CHD are given the resources and support required to take complete responsibility for their health.

FUNDING: This study was supported, in part, by the CIBC World Markets Children's Miracle Foundation Chair in Child Health Research.

REFERENCES

1. Moller JH, Taubert KA, Allen HD, Clark EB, Lauer RM. Cardiovascular health and disease in children: Current status. A Special Writing Group from the Task Force on Children and Youth, American Heart Association. Circulation 1994;89:923-30.
2. Williams WG, Webb GD. The emerging adult population with congenital heart disease. Semin Thorac Cardiovasc Surg Pediatr Card Surg Annu 2000;3:227-33.
3. Blum RW, Garell D, Hodgman CH, et al. Transition from child-centered to adult health-care systems for adolescents with chronic conditions. A position paper of the Society for Adolescent Medicine. J Adolesc Health 1993;14:570-6.
4. Harrison DA, Connelly M, Harris L, Luk C, Webb GD, McLaughlin PR. Sudden cardiac death in the adult with congenital heart disease. Can J Cardiol 1996;12:1161-3.
5. Oechslin EN, Harrison DA, Connelly MS, Webb GD, Siu SC. Mode of death in adults with congenital heart disease. Am J Cardiol 2000;86:1111-6.
6. Oechslin EN, Harrison DA, Harris L, et al. Reoperation in adults with repair of tetralogy of fallot: Indications and outcomes. J Thorac Cardiovasc Surg 1999;118:245-51.
7. Webb GD, McLaughlin PR, Gow RM, Liu PP, Williams WG. Transposition complexes. Cardiol Clin 1993;11:651-64.
8. Kaemmerer H, Fratz S, Bauer U, et al. Emergency hospital admissions and three-year survival of adults with and without cardiovascular surgery for congenital cardiac disease. J Thorac Cardiovasc Surg 2003;126:1048-52.
9. Karamlou T, McCrindle BW, Williams WG. Surgery insight: Late complications following repair of tetralogy of Fallot and related surgical strategies for management. Nat Clin Pract Cardiovasc Med 2006;3:611-22.
10. Nieminen HP, Jokinen EV, Sairanen HI. Causes of late deaths after pediatric cardiac surgery: A population-based study. J Am Coll Cardiol 2007;50:1263-71.
11. Billett J, Cowie MR, Gatzoulis MA, Vonder Muhll IF, Majeed A. Comorbidity, health care utilisation and process of care measures in patients with congenital heart disease in the UK: Cross-sectional population-based study with case-control analysis. Heart 2008;94:1194-9.
12. Reid GJ, Irvine MJ, McCrindle BW, et al. Prevalence and correlates of successful transfer from pediatric to adult health care among a cohort of young adults with complex congenital heart defects. Pediatrics 2004;113:e197-205.
13. A consensus statement on health care transitions for young adults with special health care needs. Pediatrics 2002;110:1304-6.
14. Rosen DS, Blum RW, Britto M, Sawyer SM, Siegel DM. Transition to adult health care for adolescents and young adults with chronic conditions: Position paper of the Society for Adolescent Medicine. J Adolesc Health 2003;33:309-11.
15. Blum RW. Transition to adult health care: Setting the stage. J Adolesc Health 1995;17:3-5.
16. Scal P. Transition for youth with chronic conditions: Primary care physicians' approaches. Pediatrics 2002;110:1315-21.
17. Reiss JG, Gibson RW, Walker LR. Health care transition: Youth, family, and provider perspectives. Pediatrics 2005;115:112-20.
18. Rosen D. Between two worlds: Bridging the cultures of child health and adult medicine. J Adolesc Health 1995;17:10-6.
19. Geenen SJ, Powers LE, Sells W. Understanding the role of health care providers during the transition of adolescents with disabilities and special health care needs. J Adolesc Health 2003;32:225-33.
20. Scal P, Evans T, Blozis S, Okinow N, Blum R. Trends in transition from pediatric to adult health care services for young adults with chronic conditions. J Adolesc Health 1999;24:259-64.
21. Moons P, De Volder E, Budts W, et al. What do adult patients with congenital heart disease know about their disease, treatment, and prevention of complications? A call for structured patient education. Heart 2001;86:74-80.
22. Scal P, Ireland M. Addressing transition to adult health care for adolescents with special health care needs. Pediatrics 2005;115:1607-12.
23. Por J, Golberg B, Lennox V, Burr P, Barrow J, Dennard L. Transition of care: Health care professionals' view. J Nurs Manag 2004;12:354-61.
24. Schor EL. Family pediatrics: Report of the Task Force on the Family. Pediatrics 2003;111:1541-71.