Abstract

**Purpose:** To investigate the expectations and experiences of adolescents on transferring from a pediatric cardiology program to an adult congenital heart disease program.

**Methods:** A qualitative, phenomenologic study was conducted, in which semi-structured, in-depth interviews were performed with 14 adolescents (aged 15–17 years) with congenital heart disease. Interviews were tape-recorded and transcribed verbatim. Data were analyzed using procedures described by Colaizzi.

**Results:** The study identified six themes that characterized adolescents’ views of the transfer process: leaving pediatric cardiology was viewed as normal; leaving behind familiar surroundings; a positive wait-and-see attitude toward the adult congenital heart disease program; adjusting to a new environment; a need for better information; and a shift in roles between the adolescent and his parents.

**Conclusion:** Although adolescents with congenital heart disease have a positive attitude toward transferring to an adult congenital heart disease program, they identified aspects of the transfer that healthcare professionals need to address. Patients and their families should be prepared for the transfer by informing them about the adult program and its healthcare providers. A formal transition program can play a role in this respect. © 2009 Society for Adolescent Medicine. All rights reserved.

**Keywords:** Adolescents; Congenital heart disease; Transfer; Transition; Qualitative study; Nursing

Congenital heart defects are the most common birth defects, which occur at a rate of approximately eight in 1000 births [1] and comprise a wide spectrum of simple, moderate, and complex severity lesions [2,3]. Because of advances in pediatric and interventional cardiology, intensive care medicine, and cardiac surgery, the number of children with congenital heart disease surviving into adulthood has continuously increased. To date, more than 90% of children born with congenital heart disease now reach adulthood. To meet the specific needs of this patient population and to diminish the negative impact of the condition, appropriate and experienced lifetime care for adults with congenital heart disease is needed [4]. Therefore, special programs for adults with congenital heart disease have been established.

Several international guidelines for the management of congenital heart disease state that healthcare provisions for these patients should continue without interruption as an individual transitions from adolescence to adulthood [5,6]. Therefore, a timely transfer from pediatric to adult-centered care is essential. Transfer is defined as “an event or series of events through which adolescents and young adults with chronic physical and medical conditions shift their care from a pediatric to an adult health care environment” [7]. The goal of this transfer is to maximize a patient’s function and potential through high-quality, developmentally
appropriate healthcare services. However, adolescents need to be prepared for this transfer through a transition process. In this setting, transition is therefore defined as “the process by which adolescents and young adults with chronic childhood illnesses are prepared to take charge of their lives and their health in adulthood. It is an educational process that ideally begins before children reach adolescence, and continues until they are capable of taking full responsibility of their care” [7].

Congenital heart diseases comprise a wide spectrum of heart defects. With the exception of ligated and divided duc-
tus arteriosus, all patients should continue to receive cardiac care in either a regional center or a specialized congenital heart disease program [8]. It is recommended that patients with simple heart defects, such as small atrial septal defects, patent ductus arteriosus, or small ventricular septal defects, have a medical check-up every 3–5 years [9]. Patients with moderate severity lesions, such as tetralogy of Fallot, atrio-
ventricular septal defect, or coarctation of the aorta, should have follow-up visits every 1–2 years [9]. Complex heart defects, such as all forms of cyanotic heart disease or transpo-
sition of the great arteries, require check-ups every 6 months to 1 year. Patients with moderate severity lesions, and defi-
initely those with complex heart defects, should be followed-up in a specialized congenital heart disease program, either as a child or as an adult.

Although the importance of a timely transfer from pedi-
atrie cardiology to an adult congenital heart disease program is beyond dispute, studies indicate that about one-half to three-quarters of the patients fail to continue regular follow-up when they have grown up [10]. This has resulted in a virtual lost generation. The consequences of lapse of care in patients with congenital heart disease are, however, far-reaching. Being lost to follow-up is associated with significant morbidity [11,12]. Therefore, implementation of strategies to prevent patients from failing to continue follow-up is critical. Transition programs that inform patients about the rationale for ongoing follow-up and that teach them how to navigate the medical system have the potential to avoid another lost generation.

Research on transfer and transition in adolescents with congenital heart disease is scarce [13,14]. To our knowledge, only five empirical studies on this subject have been published [11,15–18]. Three of these studies pertained to the process of transfer from pediatric cardiology to an adult congenital heart disease program [11,15,16]; one study assessed the level of knowledge in adult patients who had their first visit at the adult congenital heart disease program [17]; and one study investigated hospitalization patterns surrounding the transition from adolescence to adulthood [18]. Evidence on patients’ and parents’ perspective on the transfer to adult-centered care in congenital heart disease is even lacking. We are aware about studies that investigated this topic in adolescents with other chronic diseases, such as physical disabilities or complex health needs [19–22], solid organ transplantation [23,24], hemodialysis [25], cystic fibrosis [26], juvenile idiopathic arthritis [27], or diabetes [28]. But this issue has never been scrutinized in cardiac patients. The aim of the present study was therefore to investig-
igate the expectations and experiences of adolescents toward transferring from pediatric cardiology to an adult congenital heart disease program.

Methods

We conducted a qualitative study using a descriptive phe-
nomenologic approach. Semi-structured in-depth interviews were conducted with adolescents recently transferred or about to be transferred from a pediatric cardiology to the adult congenital heart disease program in the University Hospitals of Leuven, Belgium. In our center, it is standard practice to do this transfer when a patient reaches the age of 16 years unless the patient is medically unstable. Both pediatric cardiology and the adult congenital heart disease program are located in the same building. This facilitates the transfer of information, especially as both programs use a shared database for the clinical follow-up of patients. Formal and informal contacts between pediatric cardiologists and adult congenital heart disease cardiologists occur frequently. Catheter interventions are sometimes performed together. Although the transfer from pediatrics to adult-focused care is well established, we do not have a formal tran-
sition program in which adolescents are prepared for the transfer and to take responsibility for their care.

Patients were eligible for inclusion in our study if they had visited an outpatient clinic at least once every 2 years and if their first visit to the adult congenital heart disease program was scheduled to occur within the next 6 months. Patients with mental retardation or who were not Dutch speaking were excluded.

The study protocol was evaluated and approved by the Institutional Review Board and was performed in accordance with ethical standards, as described in the 2002 Declaration of Helsinki. Patients were included in our study only if they and their parents provided written informed consent.

A total of 25 eligible adolescents were invited to partici-
pate. Of these patients, 14 returned the informed consent form, eight patients refused to participate because they believed that they were in perfect health, and three patients could not be contacted because they had moved. Of the 14 patients who were willing to participate, four had been transferred recently and 10 were planned for transfer. The sample consisted of six boys and eight girls, aged 15–17 years. Demographic and clinical characteristics of the participating adolescents are detailed in Table 1.

The interviews were held at the participants’ homes. The opening interview question was, “How and when were you told that you had to switch from pediatric cardiology to the adult congenital heart program?” This was followed by, “How do you feel about that?” The average duration of the interviews was 38 minutes. Interviews were tape-re-
corded and transcribed verbatim. Using NVIVO 2, data
were analyzed using descriptive phenomenologic procedures that rely on step 1–6 of Colaizzi’s process [29] (Table 2).

To bolster the trustworthiness of the study, we used several different techniques [30–33]. Before the formal study, the interviewer (S.P.) had familiarized herself with the patient population and its specific needs by being employed as a specialized nurse in the adult congenital heart disease program for 13 months. This supports the credibility of the study. To avoid bias resulting from using multiple interviewers, we enlisted only one interviewer to carry out the interviews. Before the study, we also performed a mock interview to field test the questions to be used during the semi-structured, in-depth interviews. During the interviews, field notes were made to take into account nonverbal communication and context. The interviewer kept a diary in which she tried to pinpoint her own beliefs and preconceptions about the phenomena of “transfer” and “transition.” Three researchers coded the interviews individually. In a peer debriefing, all co-authors discussed the coding and made adaptations to reach consensus. Once consensus was reached, a qualitative research expert assessed the quality of the encoding. The reasons for decisions made throughout the study and analysis process were meticulously recorded.

Table 1
Demographic and clinical characteristics of the participants

<table>
<thead>
<tr>
<th>Age (years)</th>
<th>Gender</th>
<th>Frequency of follow-up</th>
<th>Type of heart defect</th>
<th>Educational level</th>
</tr>
</thead>
<tbody>
<tr>
<td>16</td>
<td>Female</td>
<td>2 years</td>
<td>Ventricular septal defect</td>
<td>High school</td>
</tr>
<tr>
<td>15</td>
<td>Female</td>
<td>1 year</td>
<td>Coarctation of the aorta</td>
<td>High school</td>
</tr>
<tr>
<td>17</td>
<td>Male</td>
<td>1 year</td>
<td>Aortic valve stenosis</td>
<td>Technical high school</td>
</tr>
<tr>
<td>16</td>
<td>Female</td>
<td>6 months</td>
<td>Tricuspid atresia</td>
<td>Technical high school</td>
</tr>
<tr>
<td>16</td>
<td>Female</td>
<td>2 years</td>
<td>Mitral valve prolapse</td>
<td>Vocational high school</td>
</tr>
<tr>
<td>16</td>
<td>Male</td>
<td>1 year</td>
<td>Hypertrophic obstructive cardiomyopathy</td>
<td>High school</td>
</tr>
<tr>
<td>17</td>
<td>Female</td>
<td>6 months</td>
<td>Pulmonary atresia</td>
<td>Art high school</td>
</tr>
<tr>
<td>16</td>
<td>Male</td>
<td>1 year</td>
<td>Transposition of the great arteries</td>
<td>Technical high school</td>
</tr>
<tr>
<td>15</td>
<td>Female</td>
<td>2 years</td>
<td>Mitral valve prolapse</td>
<td>Vocational high school</td>
</tr>
<tr>
<td>16</td>
<td>Female</td>
<td>1 year</td>
<td>Bicuspid aortic valve</td>
<td>Technical high school</td>
</tr>
<tr>
<td>17</td>
<td>Male</td>
<td>2 years</td>
<td>Subvalvular aortic stenosis</td>
<td>Technical high school</td>
</tr>
<tr>
<td>16</td>
<td>Female</td>
<td>2 years</td>
<td>Transposition of the great arteries</td>
<td>Technical high school</td>
</tr>
<tr>
<td>16</td>
<td>Male</td>
<td>1 year</td>
<td>Transposition of the great arteries</td>
<td>High school</td>
</tr>
<tr>
<td>17</td>
<td>Male</td>
<td>1 year</td>
<td>Pulmonary atresia</td>
<td>High school</td>
</tr>
</tbody>
</table>

Table 2
The seven steps of Colaizzi’s method

1. Read for general sense
2. Extract “significant statements”
3. Translate into language of profession
4. Gather “cluster of themes”
5. Write “exhaustive description”
6. Derive “fundamental structure”
7. Validate with subjects

Results

The in-depth interviews revealed six themes: leaving pediatric cardiology was viewed as normal; leaving behind familiar surroundings; a positive wait-and-see attitude toward the adult congenital heart disease program; adjusting to a new environment; a need for better information; and a shift in roles between the adolescent and his parents. Below we describe in detail these themes and illustrate them with quotes from the participants.

Leaving pediatric cardiology is viewed as normal

Adolescents considered switching to the adult congenital heart disease program when they reached 16 years old to be normal. For two participants, the transfer was deferred because of a planned operation. These adolescents indicated that this type of flexibility was good, as guaranteeing continuity of care mattered at the time. The participants could not supply any other reasons for deferring the transfer.

In the pediatric cardiology outpatient clinic it’s mostly a case of sitting about waiting in a room with noisy children aged 7 or thereabouts, whereas the advantage of the adults clinic is that it’s a whole lot quieter. I, too, am old enough now to go to the adults’ clinic…. Last year, you see, when I went for a checkup, I sat there amidst all those small children and babies, which makes you wonder: why am I still in this group? I would prefer, at my age, to be in with the adults.

The adolescents were unable to indicate exactly what had made them ready for the transfer. This was true for both participants who already transferred and those who were yet to be transferred. They believed that they were too old to be followed up in the pediatric clinic. Only two participants (two girls) stated they had noticed that other issues had emerged, such as pregnancy and contraception.

Leaving behind familiar surroundings

Many adolescents commented that their parents found the transfer to be more difficult than they did, because parents had to develop a new trust-based relationship with the
cardiologist at the adult congenital heart disease program. An active relationship between the pediatric cardiologists and the adolescents developed later in life. Indeed, at the pediatric cardiology clinic, adolescents were active in the patient–doctor dialogue for only a couple of years. They were satisfied with their level of care at the pediatric cardiology clinic and felt that they were leaving familiar surroundings.

Oh, I’ve got used to those physicians by now. Granted, I only go there once a year but they do remember you, you know…. I also know them quite well by now and want to say my goodbyes properly. You do have a certain bond with them, you know.

The two adolescents that deferred their transfer because of planned operations remarked that they would return to the pediatric cardiology clinic one last time to thank the doctors and to say goodbye. By contrast, the remaining participants considered this to be a “closed chapter” and did not feel the need for a farewell visit. One of the adolescents who underwent an operation before the formal transfer to the adult congenital heart disease program was hospitalized in an adult ward instead of a pediatric ward. This participant experienced the transfer to be abrupt.

I was put in an adults ward. Humph, I was the youngest person on the ward and the oldest patient was 85! All those old ones just lay there all day, coughing. Before long, you start to wonder, ‘Just what am I doing here?’

A positive wait-and-see attitude toward the adult congenital heart disease program

The adolescents had a positive wait-and-see attitude about transferring from pediatric cardiology to the adult congenital heart disease program. Most of the participants in this study were yet to be transferred, but they remained calm and did not dread the prospect because they expected little difference between the two settings. They grew up with the knowledge that lifelong monitoring is vital to promptly detect possible complications, both now and in the future.

To tell the truth, that transfer will make little difference. I can’t see it being much different from the system I know now…. Let’s sit back, relax, and see what the future brings. Hey, why should I worry my head about that? It’s something that has to happen for the rest of my life anyway. Pshaw … that makes no difference, really. It’s just a checkup, like any other.

Adjusting to a new environment

Although the adolescents indicated that they did not worry about the transfer, they were curious about what lay ahead of them. In the beginning, they would need some time to adjust to the adult program. The first contacts with the adult congenital heart disease program represent a decisive factor for a successful transfer.

It’s all new to me, so it’ll take some getting used to. It’ll take two to three sessions, I reckon, before I get over my initial nerves and apprehension…. I can’t for the life of me think how it’s going to be any different than before…. But everything will become a lot clearer the first time that I really have to go…. I will turn up there, expecting the necessary information and, hopefully, everything will drop into place…. I will bide my time until my first session and then take it from there.

Some adolescents who had yet to be transferred wanted more general information about the adult outpatient clinic. They wanted to know where the outpatient clinic was, who they were going to meet there, and what was on the agenda. Not all adolescents realized that the next outpatient visit would be held somewhere else in the hospital. Adolescents who were already transferred highlighted some key differences between pediatric cardiology and the adult congenital heart disease program. They were, for example, unaware that the two outpatient clinic settings—pediatric vs. adult—had a different sequence of the stages: e.g., electrocardiogram, echocardiogram, nurse specialist, cardiologist, etc. Although they acknowledged a need to adjust, they also wanted to be informed about these differences. This led to the identification of another theme: a need for better information.

A need for better information

Adolescents who had had their first visit at the adult program were satisfied with the treatment they received but stated that, in retrospect, they had been largely unaware of what the outpatient visit would entail. Differences with the pediatric cardiology clinic were of an organizational nature. Both the adolescents and their parents were unsure of whether parents were allowed to be present during the contacts with the healthcare providers.

It all went very smoothly; everyone was friendly and most helpful and gave a lot of information. My only gripe is that I didn’t know what was going to happen in advance and I did find that a bit awkward…. The feeling my parents had after I’d gone inside was: ‘Oh, we’d thought you’d gone in that door for an ultrasound scan.’ But that was far from the case…. It was all a bit unexpected…. I walked in and was unsure whether my parents were allowed in with me or not. They stayed outside and didn’t know where I’d gone exactly or what for….

A shift in roles between the adolescent and the parents

Adolescents expected the information they received during the outpatient visit to be directed to them. They wanted to be heard. On the other hand, they still had the same expectations toward their parents in that their parents should be kept posted of all developments, as they were still the first point of contact if a problem should occur. They thought that nonmedical issues should also be addressed.

My parents didn’t get the message across to me. At any rate … it’s of great importance to me that the doctors
don’t just examine my heart, but take in the whole person…. At the tender age of sixteen, it’s not as if you’re truly an adult yet. You’re not self-sufficient yet. You still live with your parents. They provide and care for you and still know everything about you. You’ve almost reached adulthood, but if there’s something on your mind, you still turn to your parents.

It was obvious that the adolescents were not always knowledgeable about their heart defect. Some adolescents may have had no understanding of their medical condition. Indeed, up to this point, their parents had more information than they did.

At the pediatric cardiology clinic, my mother went inside to speak to the doctor and I had to wait outside. So I had no knowledge of what was said. It wasn’t until the last two visits that I was allowed to accompany her into the doctor’s office…. So it’s all a big blur what they did to my heart all those years. Now that I’d got face to face, as it were, I asked them for clarification and, at long last, they gave me a full explanation. My parents knew more about what was wrong with me, but even they weren’t privy to everything.

Discussion

The stage of adolescence and emerging adulthood is a critical period for establishing lifelong health-related behaviors, due to specific developmental issues, such as identity development, autonomy, and coping with the altered parent–child relationships. This is particularly true in youngsters with chronic conditions. It is important to understand how adolescents with chronic conditions tackle developmental tasks, because it determines the transitional needs of the youngsters, and it permits researchers and clinicians to develop the most appropriate and patient-oriented method for transitional care.

Numerous articles on transfer and transition have been published over the past decade. The majority of these publications report nonempirical work [34]. The number of empirical studies on transfer and transition in adolescents with congenital heart disease is very limited [13,14]. Therefore, we undertook a qualitative study, using in-depth interviews, to investigate the expectations and experiences of adolescents with congenital heart disease with respect to being transferred from pediatric cardiology to an adult congenital heart disease program. This is, to our knowledge, the first study of this kind in this patient population.

The results showed that adolescents with congenital heart disease considered it to be normal to leave pediatric cardiology when they grow up. Adolescents believed that the adult congenital heart disease program was more appropriate for them than pediatric cardiology, because they deemed the approach and the environment to be more adapted to their needs. Therefore, they had a positive wait-and-see attitude toward the adult congenital heart disease program. Nonetheless, adolescents noted that the transfer from pediatric cardiology to the adult congenital heart disease program involved leaving behind familiar surroundings. Therefore, they needed time and resources to adjust to the new environment, and they required adequate instruction and information. This suggests that a formal transition process that prepares adolescents and their parents for the transfer is important. Finally, adolescents in our study were aware about shifting roles between themselves and their parents. They realized that they were gradually taking on responsibility for their own health. Therefore, healthcare professionals should direct communication to the adolescent. However, the adolescents did not want their parents to be overlooked. The parents remained the first resource in case of questions or problems.

The adolescents apparently were not bothered about being transferred to an adult congenital heart disease program. They indicated, however, that their parents found it harder to cope with the transfer. Indeed, in clinical practice, parents report that they had developed a trust-based relationship with the pediatric cardiology providers, and often considered pediatric cardiologists and cardiac surgeons as the ones who saved their child’s life. Thus, the transfer from pediatric to adult cardiology is apparently more difficult for them than it is for their children, who view the transfer as a logical step in their lives. Although we cannot confirm this in the present study, we hypothesize that the severity of a child’s heart defect and the frequency of contacts with the pediatric cardiology clinic during adolescence are major factors in the experience of leaving pediatric cardiology as a familiar surrounding.

Unlike previous studies, our investigation would give the impression that the transfer to adult services is not a problem. It should be noted, however, that we investigated only adolescents’ perceptions with respect to the transfer. From prior studies we know that the transfer to the adult care facilities is not always successful, resulting in a lapse of care [11,15,16,35], and that patients are not always prepared for the transfer yielding a lack of knowledge [17,36,37]. In addition, parents may have more difficulties in coping with this transfer than their youngsters. Hence, transfer and transition are important issues that have to be studied from different perspectives.

Our findings are to some extent in line with the results of studies on adolescents’ experiences performed in other patient populations. In general, the transfer to an adult-focused care program is a positive experience for adolescents, because they are recognized as responsible young adults [38]. They want healthcare staff to address them instead of their parents; they want to be spoken to in an adult manner; and they want to be responsible for their own care [24]. Indeed, most adolescents perceive pediatric services to be condescending and inappropriate for their needs [39]. However, leaving pediatric services is not easy [24,39]. Familiarity with pediatric services, environment, and healthcare workers, as well as unfamiliarity with the adult care environment and providers, may make some adolescents reluctant to transfer [39]. Therefore, the transfer to an adult care program requires adequate preparation [23,38,39]. Young adults who transfer to adult care need to be prepared
for the adult center, to be made aware of the differences, and to be introduced to team members before the transfer [23]. This preparation is considered to be the responsibility of the pediatric care team [26].

Although the results of our study correspond to a certain extent with previous findings, they are not completely comparable. This might have to do with the setting in which our study was conducted. In our hospital, follow-up of both adults and children take place in the same building. This facilitates the transfer of information, especially as both programs use a shared database for the clinical follow-up of patients. Formal and informal contacts between pediatric cardiologists and adult congenital heart disease cardiologists occur frequently. The facts that patients and their families do not have to change hospitals and that pediatric and adult care providers do have formal and informal contacts appear to make it less problematic for adolescents to move their care to the adult-focused program. Furthermore, Belgium has a compulsory health insurance system, covering almost the entire population. The system is emphasizing solidarity. There is absence of price competition among healthcare providers; lack of insurance is nonexistent; and access to healthcare is high. Presumably the transfer is more challenging if pediatric cardiology and adult congenital heart disease clinics are located in different hospitals, or when other health insurance and reimbursement policies are applicable. Future research should be conducted under such settings.

Methodologic limitations

Some methodologic limitations lead us to interpret the results of this study with caution. Of the 25 adolescents who were invited to participate in our study, only 14 consented. This relatively high refusal rate could indicate that, at the time of the study, many of these youngsters experienced little trouble with their disease, with next to no limitations. In the included patients, the majority (n = 7; 50%) had a heart defect of high complexity, whereas in patients who refused to participate or those who could not be contacted only three of them (27%) had a lesion of great complexity. The proportion of trivial heart defects was comparable in both groups. This means that there might be a selection bias in our study, with an overrepresentation of severe conditions.

Furthermore, this study was conducted at one hospital in which both pediatric and adult cardiology programs are located. Therefore, our results cannot necessarily be generalized to the entire population of adolescents with congenital heart disease, or to settings in which pediatric and adult care is provided in different settings.

Although the last interviews that we conducted did not reveal new information, we cannot conclude that data saturation was reached. For instance, we interviewed only one adolescent who was hospitalized in an adult ward during the transition phase. Further research is needed to determine how the transfer is perceived when patients are hospitalized. Moreover, it should be investigated whether the adult cardiac care is experienced to be appropriate to meet the adolescent-specific needs.

The present study focused only on the perspective of adolescents. Higgins and Tong asserted that the transition process for adolescents with a congenital heart defect should be analyzed from four different viewpoints: those of the adolescent, the adolescent’s family, the pediatric cardiologist, and the adult congenital heart disease cardiologist [40]. In this respect, we recommend adding the perspective of nurses and transition coordinators. Further research is necessary if we are to fully comprehend all of these stances on transition.

Conclusions

In conclusion, we investigated the expectations and experiences of adolescents with congenital heart disease about transferring from pediatric cardiology to an adult congenital heart disease program. We found that adolescents consider leaving pediatric cardiology to be normal and have a positive wait-and-see attitude toward the adult congenital heart disease program. However, the transfer from pediatric cardiology to the adult program is associated with leaving behind familiar surroundings. Therefore, adolescents need time and resources to adjust to the new environment. They also require adequate instruction and information. Finally, adolescents acknowledge that this shift in care also involves a shift in roles between themselves and their parents.

Acknowledgments

The authors gratefully thank Mathieu Dejonckheere and Idalie Vandamme for their assistance in the transcription of the interviews. This study was financially supported by the Jacqueline Bernheim Award 2005 (to P.M.).

References


