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“It's No Big Deal”: Adolescents With Congenital Heart Disease¹

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Improved survival rates for congenital heart disease (CHD) have increasing numbers requiring lifelong specialized health care. In this interpretive description, interview data were analyzed to understand how adolescents with CHD describe everyday life and relate to questions about quality of life. Most viewed themselves as normal, their CHD something that they situated into the foreground or background of their lives as it suited their needs. They spoke of quality-of-life issues in a concrete manner focusing on physical activity limitations and their need to fit in. These findings can direct interventions for adolescents with CHD for transition to adulthood.

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INDIVIDUALS WITH COMPLEX congenital heart disease (CHD) now live well past childhood and even into adulthood (Moons, Budts, & De Geest, 2006). Each year in the United States, 40,000 newborns are affected by CHD (Connolly, Rutkowski, Auslender, & Artman, 2002). Up to 90% of these newborns (Claessens et al., 2005) will survive into adulthood, increasing the need for appropriate health services for this emerging population of adults with CHD (Canobbio, 2001). These individuals have unique medical, social, emotional, and functional needs as they move forward with their lives (Hudsmith & Thorne, 2007), and their parents and health care practitioners face new challenges (Gabe, Olumide, & Bury, 2004). Despite remarkable advancements,

there remain considerable morbidities for adolescents with CHD that must be addressed as they anticipate adulthood. The main causes for hospital readmission in grown-ups with CHD are arrhythmias, heart failure, pulmonary vascular disease, endocarditis, and reoperation. A specialized plan of care that addresses the needs of teens transitioning into adulthood is necessary because of essential cardiac care beyond adolescence (Huang et al., 2011).

Given the health concerns for adolescents and young adults who have survived their CHD, quality of life has received attention (Macran et al., 2006), but the adolescent's perspective is not being sought (McMurray et al., 2001; Pike et al., 2007). Children and teens at times have a point of view contrary to their parents regarding symptoms of the disease, thus leading to differing perceptions about the adolescent's overall quality of life (Connolly et al., 2002). The World Health Organization has recognized that quality of life is a subjective experience, defined as “individuals' perceptions of their position in life in the context of the culture and value

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systems in which they live, and in relation to their goals, expectations, standards, and concerns” (Szabo [WHOQOL Group], 1996).

Indirect measures of quality of life such as exercise tolerance and/or the parents’ perspective of their child’s quality of life have been used (Gratz, Hess, & Hager, 2009; Sparacino et al., 1997). Direct measures to quantify quality of life of teens living with CHD have been developed (Macran et al., 2006; Uzark, Jones, Burwinkle, & Varni, 2003; Varni, Seid, & Rode, 1999), and studies utilizing these measures are appearing (Macran et al., 2006; Varni et al., 1999). Qualitative methods have also been employed with teens to elicit their perspective on their quality of life (Kools, Gilliss, & Tong, 1999; McMurray et al., 2001; Tong et al., 1998). The past research, both quantitative and qualitative, has focused on cardiac aspects of these teens’ lives, such as hospitalization and limitations related to CHD. As quality of life potentially encompasses all facets of one’s life, it is important to consider the teens’ voice concerning their perspectives on and reflections of their everyday lives living with CHD. As teens with chronic health conditions, including CHD, struggle to gain independence in their lives, they may also struggle with the reality that their lives are different from those of their healthy peers and that their futures will be different. Clinicians, however, often miss the mark or neglect to see what the salient issues are for these teens (Connolly et al., 2002). The research literature identifies psychosocial, physical, knowledge, and quality-of-life issues.

Regarding psychosocial issues, McMurray et al. (2001) focused on the *experience* of living with CHD, not quality of life per se. They found that the adolescents’ “less ordinary life” stemmed from issues of coping, limitations, exclusion, discrimination and bullying, and hope for life improvement. They concluded that greater attention to psychosocial needs is necessary. An exploratory descriptive qualitative study with 13- to 25-year-olds identified several psychosocial issues: dilemmas of normality, of disclosure, and of finding strategies for illness management, and challenges of social integration versus social isolation, of dependence versus independence, and finally, of uncertainty. Developing strategies for coping, low self-esteem, anxiety, and depression was also identified as a major issue (Tong et al., 1998). Claessens et al. (2005) examined the lived experience of adult patients with CHD. The feeling of being different was predominant among the young adult subset as they struggled to achieve a sense of normalcy.

Adolescents with CHD have concerns with their physical bodies. They described physical characteristics that visually set them apart: cyanotic lips, small stature, and surgical scars (Tong et al., 1998). McMurray et al. (2001) found that they defined many of their problems in terms of impairment, indicating that their social exclusion was because of their physical characteristics such as decreased stamina and limited ability to keep up. Other physical characteristics typical in young adults with CHD were

breathlessness, decreased endurance and pace, and a need for more frequent rest periods. These all limited the interviewed adolescents’ ability to participate in physical education, after-school sports teams, horseback riding, bicycling, and scuba diving (McMurray et al., 2001; Tong et al., 1998). The regular day-to-day activities that healthy adolescents take for granted become off limits for some adolescents with CHD, thus potentially leading to feelings of social exclusion. Missing from the literature was any direct reference to whether feelings of exclusion factored into their quality of life.

Regarding knowledge issues for teens with CHD, a descriptive, cross-sectional study of adolescents with CHD (Van Deyk et al., 2007) found significant gaps in adolescent’s knowledge of CHD and how it affected their lives. For example, less than 50% could name their heart defect, follow-up needs, medication plans, and symptoms that would indicate a worsening of their heart condition. Teens with CHD and their parents stand to benefit from increasing their knowledge specific to the issues they will encounter as they begin transitioning into adulthood.

Quality of life is increasingly being considered concerning children, teens, and adults with CHD (Eiser, Mohay, & Morse, 2000; Latal, Helfricht, Fischer, Bauersfeld, & Landolt, 2009; Loup et al., 2009; Macran et al., 2006). Regardless, reviews of pediatric cardiology literature found that limited research had been done on the quality of life in patients with CHD, especially as it related to social functioning and overall well-being (Green, 2004; Pike et al., 2007). The existing research on quality of life in adolescents with CHD also underrepresented the adolescents’ point of view. Moons et al. (2006), in their review of quality of life in pediatric cardiology, were concerned that consensus has not been reached about the exact determinants of quality of life. This can lead to problems when determining which tool to use to measure quality of life. Moons et al. defined quality of life broadly in terms of satisfaction with life, a concept that “corresponds to overall quality of life and is not limited to health-related quality of life” (p. 898). The teens’ perspective about all aspects of their life, not just their CHD, is considered.

In summary, the adolescent point of view has not been well studied, nor have questions been asked about whether quality-of-life questionnaires reflect adolescents’ concerns. Nurses are well positioned to gather and disseminate knowledge from an exploration of quality of life as understood by teens. The purpose of this study was to understand how adolescents with CHD describe their everyday life and relate to questions about quality of life.

Study Design and Methods

Teens were asked about their CHD as it related to their everyday life in this interpretive description study (Thorne,

2008). Interpretive descriptions “represent the foundation for nursing’s theoretical structure and its substantive body of knowledge” (Thorne, Kirkham, & MacDonald-Emes 1997, p.173). Interpretive description made it possible to look beyond *what* constituted quality of life and to focus on *how* and *why* different issues affected the teens and what having a life of quality signified for them.

Sample and Data Collection

The sample consisted of 10 adolescents (six females) who were 13–17 years of age at the first interview, with a range of cardiac diagnoses for which they had each had at least two heart surgeries. Despite the diversity of diagnoses, timing of treatment, and family configuration, commonalities and shared experiences emerged early in the data collection and analysis. Data were collected using semistructured interviews with the teen alone. Interviews were 45 to 120 minutes long. One teen participated in 1 interview, 6 participated in 2 interviews, and 3 teens participated in 3 interviews, for a total of 22 interviews. Ten interviews took place in the participants’ homes, 7 were by telephone, and 5 took place in conjunction with the teen’s appointment at the university hospital. Most of the interviews were conducted by the second author or the project coordinator, both with pediatric nursing backgrounds and extensive qualitative interviewing experience. Teens completed the Pediatric Quality of Life Inventory (Varni et al., 1999) and the cardiac module developed by Uzark et al. (2003) at the second interview. The scores from these surveys were not a source of data for this study, but filling out the survey was an activity to elicit conversation about their quality of life and to ascertain whether such a tool could be useful for youths with CHD as a relevant way of identifying quality-of-life issues from their perspective. The two approaches, semistructured interviews that included numerous open-ended questions and the questionnaire activity, were used to capture how teens with CHD talked about and reflected on quality-of-life issues. Guiding questions are provided at the end of the article. The first and second authors worked closely in the data analysis and received input from the other authors regarding conceptualization and conclusions.

Data Analysis

Interpretive description holds that theories about a clinical phenomenon are not preconceived notions, but rather “must emerge from or be grounded in that phenomenon” (Thorne, 2008, p. 74). The initial step was to understand the different pieces of data, then to identify the emerging patterns of data, and finally to make sense of the relationships between these patterns to identify the major themes. This involved listening to electronic versions of the interviews and reading interviews that were transcribed verbatim. Through the process of moving in and out of the data, themes and patterns

emerged followed by development of a coding scheme, which was then applied to the interview data (Thorne, Reimer Kirkham, & O’Flynn-Magee, 2004). Ten code categories with several subsequent secondary categories were developed, from which the main themes that constituted the findings were identified.

Gathering data from teens with varying diagnoses through a variety of methods is one way of ensuring validity and aids in yielding trustworthy data. Remaining true to the stories gathered in this study contributed to validity and ensured that meaning was not changed or adjusted to fit with ideas emerging from other participants’ data. Every effort was made to attend to the participant’s exact wording so as to portray the intended meaning.

Findings

A commonality among the teens was their willingness to articulate what it was like to grow up with CHD. The teens spoke openly of their life at school, at home, at work, at play, and as cardiology patients. Overall, these teens related to the concept referred to as quality of life, but they did so indirectly, and as such, more questions were required from the interviewer than simply “How would you rate your quality of life?” As is often the case with qualitative research, hearing the stories directly from the teens created the opportunity to understand how growing up with CHD had affected them both in terms of day-to-day life and quality-of-life issues.

Quality of Life: “It’s Like How You Enjoy Life”

Understanding quality of life conceptually did not come easily to this group of teens, as would be expected given their development and ability to comprehend the abstract nature of this concept. The actual term *quality of life* did not resonate with the teens. For the most part, they talked about quality of life in broad terms that did not relate to their lives. They described it as how good or bad your life is and how happy you are. Two teens referred to a definition of quality of life that they were taught in Grade 9 social studies, “It’s like, how you enjoy life,” or referring back to a country’s quality of life and comparing that to an individual’s quality of life:

[It is] how happy the person is and how well they are and how easy it is [for] them to get like medical treatment and are they educated compared to like other countries? Are they just as well or mediocre compared to other countries? You don’t always have to be the smartest or the best at everything. It’s more like are you average? Are you happy?

Regarding the question of how teens with CHD relate to questions about quality of life, this was done in an indirect

manner through stories of their day-to-day life that reflected a surprising degree of satisfaction with their lives.

Physical Differences: “It’s No Big Deal” to “I Could Die”

Accounts of their day-to-day life as an adolescent with CHD provided data about aspects that affected how they viewed themselves, especially related to physical characteristics. The two areas of difference from peers were around actual involvement in physical activities and body image. Of the 10 teens, 7 stated they had no physical restrictions placed on them by their physicians or parents. They took part in a variety of after-school activities such as soccer, volleyball, basketball, and dirt biking, indicating that on the surface, these teens were no different from their peers. However, these teens imposed physical restrictions on themselves. They combined knowledge about their CHD and common sense to determine when they felt they were pushing themselves too hard physically. One teen stated, “Like half the time they [his parents] think I shouldn’t participate in gym but like I do anyway cause like I’ll know if it’s something I can’t do and if it’s too much.” This sentiment was shared by one of the more active teens in the study who talked about getting tired after running for over an hour, which he felt was potentially heart related, and so therefore knowing when to take a break.

Three teens reported physical restrictions and the reasons for this varied. For one teen, this was related to his anticoagulation therapy. He was careful vis-à-vis physical activity, “[because] I can’t get hit in the head,” which even precluded him from swimming. He felt he could die if he hit his head in the pool, in stark contrast with another teen who took Coumadin. She was to be more careful than her peers, but, “I’m not really; if I fall it might be a bigger bruise.” It was difficult to tease out what contributed to activity restrictions. For less-active teens, lack of participation in physical activities seemed in part because of their lack of interest. Teens also associated their lack of physical activities to being “lazy.” One teen did not participate in gym class because of her “laziness,” not because of her CHD. Another participated in sports when he was younger but was “lazy now” and chose not to be as physically active.

In terms of body image, all but one participant, a male, spoke about their scars, but the comments varied from teen to teen. For the males, one was nervous about showing his body, and the other two were not bothered. One stated, “If they’re all like ‘Let’s see your scar?’ I’d be like okay and I’ll just pull down my shirt, you know. Like it’s no big deal.” The females were conscious of their scars and covered them up depending on the circumstance. There was discussion of the type of shirt one wore, a high neck or a V-neck, and to whom the girls felt comfortable showing their scars. Two girls commented on the awkwardness of swimming and what type of cover-up was necessary. One remarked that, “I think

about it a lot when I’m going there [swimming] and then once I’m there, I don’t even remember it; I just continue on.” Teens felt comfortable enough around both family members and close friends to reveal their scars without concern. These teens had their scars from birth with some new ones added along the way. They knew themselves in no other way and recognized that friends and family also knew them in this way. One teen stated that, “we have this resort...where it’s a little village with everyone we’ve known since I was born so everyone there is really protective and fine over it [the scar] and they don’t mind.” The teens were hesitant in allowing schoolmates to see their scars, being more concerned with how this group would react than any other group. In the school setting, five of the teens felt the need to cover their scars so as not to be a target for bullies. The youngest teen, for example, only wore t-shirts with high necks at school because: “I’m just scared that they’ll [classmates] be like oh, like make fun of me or something.” This was a bigger issue when they were younger, as presently many of them now were less concerned about how others viewed them. Two other girls spoke of the embarrassment of having their school peers see the scars but were unbothered by strangers seeing their scars.

CHD: Background and Foreground Considerations

A major finding of this study was the teens’ striking capacity to situate their diagnosis of CHD into the foreground in some situations and in the background in other situations. CHD became a card that they could play when it suited their needs. For example, the teens spoke of their involvement in gym class where CHD became a foreground issue when they did not want to participate. Conversely, they talked about being “normal” teenagers, with normal everyday concerns. In those accounts, CHD was situated in the background. Teasing out the theme of foreground/background by considering how the teen related to him or herself individually, to family and friends, and to health care professionals furthered the data interpretation.

The Individual Level: “It’s Just Like a Regular Life for Me”

Living with CHD was not something many teens considered as being a defining aspect of their life. One young teen said, “it’s just like a regular life for me. Nothing really different goes on except sometimes I get tired more often now and like I still have lots of friends to talk to.” The important things at this stage in her life were fitting in and having friends. Their health care needs did not necessitate them situating CHD in the foreground of their day-to-day life. Doctors’ appointments ranged from every 6 months to every 2 years. Of the 10 teens, 6 took no medications or only a baby aspirin once a day, and prescribed activity restrictions were not common. These teens spoke of their physical health as a minor

detail in their daily lives. When her last surgery 6 years ago was discussed, a 15-year-old showed little concern stating:

Well I never really paid attention to it [CHD] in the first place 'cause I've, ever since I remember, I've had it so it's not like I can tell you about a time when I didn't have it. So it's not like it really matters, or it's just a part of me now 'cause I grew up with it.

This comment captured the reality of everyday life for these teens and the extent to which CHD was a part of them. This diagnosis and its sequelae were woven in and out of the teens' stories in such an instinctive manner as to allow their audience (be it a family member, friend, or health provider) to also place the heart problem in the background—out of the way of the normal life.

Conversely, there were circumstances in which teens situated their CHD diagnosis into the foreground, making a clear case for themselves as different from their peers. This most commonly came up when the teens discussed physical activities and more specifically gym class. The teen who wanted to avoid gym class would tell substitute teachers: "I'm like 'I'm tired. I can't breathe. You know I had a heart disease,' and so that's always the subs that I say that to sometimes, so I get out of it." This teen portrayed herself as similar to her peers, yet she brought her CHD diagnosis to the foreground to avoid an activity she did not enjoy. She was able to use the CHD card to her advantage, in direct contrast to how she used it in the other situations where she spoke of CHD as being a part of her life to which she did not pay attention. As the teens endeavored to understand the role CHD played in their everyday lives, they situated this diagnosis from the foreground to the background in a reflexive manner that they may not even be aware of, playing the CHD card in some situations, and not in others.

At Home, at School, and in the Community: "They Get All Ask-y About It"

When the teens talked about their life at home with their family and at school with their friends, there was considerable variation on their CHD being a foreground or a background issue. This seemed consistent with their developmental stage of striving to separate themselves from their peers and families while still needing the protection of being a member of a large group. This was most evident when the teens spoke of how they chose to disclose the details of their heart health history to their family (both immediate and extended) and to a selected few at school and in the larger community. How many details disclosed and the manner in which they conveyed these details depended on whom they were with and the nature of their interactions.

The teens often did not disclose details of their CHD when interacting with people they did not know or with whom they did not get along. For one teen, talking about her diagnosis and subsequent heart problems was a personal thing that she would disclose to close friends but not to everyone. She reported telling others about the surgery she had when

she was 9 years old but not about the surgery she had when she was 2 years, "unless it really, really matters." This teen felt uncomfortable and "mad" when "they get all ask-y about it." The curiosity of others did not always match her desire to disclose. By giving out selective information, she felt in control of how much people knew and could keep as much of it in the background as she desired.

In the community setting, there were several examples of teens wishing for their heart problems to remain private. Notably, an older teen spoke of weird looks he would receive when he wore a basketball jersey that made his scar visible. When this happened, he would push himself hard to prove that his ability to play basketball was unhampered by his CHD. His heart problem took a backseat to his abilities as a basketball player and as such enabled him to situate that diagnosis in the background and demonstrate his resolve to not let CHD direct his life.

As much as these teens wanted privacy concerning their CHD, they also provided examples of the opposite. When one of the older teens discussed the best thing about growing up with CHD, he focused on how much extra attention he received in elementary school. He fondly recalled the extra attention he received from teachers and friends. So although he particularly emphasized that he was "just like a normal 16-year-old kid," his CHD had a prominent place in his life. There were times when the teens did not mind the CHD situated in the foreground.

When it came to disclosing details of their heart condition to peers and teachers at school, the teens had different approaches. Although some of the teens felt that their CHD was a private affair, others were happy to disclose details. One teen grew up in a small town and knew everyone in his school. He was unconcerned with disclosing the details of his heart condition. When people saw his scar and asked questions, he felt at ease answering, even with someone new to his social circle. His CHD was brought forward as a foreground issue both by him and by others. Each individual's personality influenced use of CHD as a foreground issue.

The Health Care Setting: "I'm a Lot More Used to Doctors and Everything"

The data related to the health care setting brought to light the lived reality of the health problems these teens had grown up with and how the teens worked to assimilate their health problems into everyday life. From an outsider's perspective, missing school on a regular basis, taking medication before routine dental appointments, and staying overnight in hospitals are not part of a normal child's upbringing. Yet, these teens' attempts to normalize these activities seemed necessary to make sense of it all. When the teens spoke nonchalantly about their appointments and various visits to the hospital, they conveyed a message that their CHD was a background issue. This reflex or automatic process was no different than what they had done in other situations where they presented themselves as "average" teenagers. Growing

up, these teens had a regular (yearly or more often) routine of medical appointments, blood work, and tests (i.e., echocardiograms, MRIs, and CT scans), and this routine was a background issue for them. It only became a foreground issue when a new test was being done or when the routine was interrupted such as when a teen went to a doctor's appointment with the parent who did not usually come.

Of the 10 teens, 8 conveyed a sense of comfort with both hospitals and the health care providers they had encountered. The terms *used to it* [the hospital], *used to them* [the health care practitioners], and *comfortable with* came up repeatedly. One teen reported that, "I'm a lot more used to doctors and everything. Needles don't bother me or anything." He indicated that he did not spend a lot of time in hospitals anymore. Another teen's response to a question related to the best thing about having CHD was that she got to spend more time in the hospital than other kids, that she knew her doctors and they knew her and that it was not scary for her at all.

It's just when I go there, I don't feel [pause]—like sometimes I feel a little bit different at certain places. Like at the pool I feel different, and then when I go there [hospital/clinic], it's just normal and people there have, might have the same thing as me or people there have a different thing but no one judges you or expects anything. They all see you as a kid who is at the hospital.

Her CHD was a background issue when she was in the hospital. Going to the hospital, a place she described as "homey," was not anything out of the ordinary.

A notable exception to this comfort was one teen who was being seen frequently for CHD-related complications and was the only one in our study transitioning to adult care. He was straddling two worlds, having seen a new (to him) pediatric specialist for his first three or four appointments and then switching over to an adult specialist for subsequent visits. He spoke of the difficulties and of his experience with the adult care:

You don't learn as much so far, you don't learn as much when you're, ah, when you're going into the adult. So it's kind of different. Well it's way different cause you can't, they don't take as much time with you because they already think that you should, you should know it, but I'm still only 17.

He had difficulty communicating with the doctors and nurses so it is not surprising that he found it uncomfortable to go to his doctors' appointments. This situation exemplifies that teens were not always the ones deciding to make CHD a foreground or background issue.

There were other situations where the teen lacked control over whether CHD was a background issue. CHD became a foreground issue when the boundaries of what the teens deemed to be normal were breeched, such as when a new test was necessary or when they saw the doctor on their own for the first time. For one teen, an additional new test was done while he was anaesthetized. On two separate occasions, he

mentioned that he had not been told (prior to being put to sleep) about the additional test and how upset he was by this. Understanding what was going to occur during each appointment was an important feature of the doctor–patient relationship and helped build trust. When this trust was broken, the CHD diagnosis and its sequelae were suddenly brought to the foreground.

For another teen, changes came with her first CT scan, MRI, and stress test. This participant was one of the few teens in the study who openly expressed a growing desire to start going to her tests and doctors' appointments alone. Having an echocardiogram or an ECG were nonissues for her. However, her first stress test was booked on a day devoted to adults with CHD, and she and her parent were surrounded by adult cardiac patients in the pediatric cardiology clinic area.

It was an abnormal day because it was on like a Friday so not all the normal people were there cause I never knew that adults actually went to that place. Like, I didn't know that. Like 'cause all of a sudden I was like with like 30-year-olds and I was like "Okaaay." Yeah, and I always thought they just took like kids and then afterwards they just sent it away. So it was weird. I was confused and my [parent] like was sitting there with me and [was] like "Where's all the children?"

Her use of the word *abnormal* highlighted the precariousness of the situation, where the normal world could be upset by a minor change. The CHD diagnosis, although often in the background of these teens' minds, could easily be brought to the foreground.

Discussion

Learning how best to approach life's obstacles is a task for all teens as they enter young adulthood. With changing minds and bodies, the teens in this study were faced with the additional obstacle of growing up with CHD. A striking characteristic of the 10 teens was their overriding sense of self as being similar to their peers and friends. This was present regardless of age or developmental level and granted them a sense of satisfaction with their life that we conceptualized as quality of life for them (Moons et al., 2006). This was in contrast to their history of serious CHD and their need for ongoing care and monitoring from cardiac specialists. On the surface, these teens came across as perceptive individuals who had learned to take their early-in-life CHD diagnosis in stride. Although their CHD did mark them as different from their peers, each teen described the ways in which they saw fit to portray a life of normalcy. Similar to their healthy peers, teenagers with CHD met developmental milestones, completed school work, and were in the process of formulating hopes and dreams for the future. However, certain elements of their lives set them apart from their peers: their physical activity levels, their scars, and their relatively frequent

interactions with health care practitioners. The three main points of discussion that have arisen for further examination relate to normalization, physical activity, and choices about CHD as a foreground or as a background issue. An understanding of quality-of-life issues and where and how they come into play is also addressed.

Am I Normal or Am I Different?

For the teens in this study, fitting in and not sticking out contributed to their quality of life. The ability to accept themselves for whom they were revealed a satisfied sense of self. Their scars served to remind them that they were different from their peers, but maintaining a sense of normalcy throughout their daily lives was a priority for them. Claessens et al. (2005) found that this process of normalization was dynamic and varied throughout the lives of adults with CHD. CHD was not a problem for those who had learned to live with the restrictions, but there were others who were unsuccessful at adapting to the limitations of their disease. The teens in this study saw themselves as normal and thus were adapting. These teens, like their peers, were working at coming to an understanding of their role both within their family and within the greater society. In other words, they were developing a sense of themselves as individuals, different and apart from their family, their peers, and society as a whole. This dialectical process is one that takes place over several years and involves a gradual progression toward independence, and there was evidence of this process in the data. This increase in independence was more related to maturity and developmental level than age.

Unlike the findings in our study, Tong et al. (1998) found that despite attempts to lead a normal life, the teens they interviewed found it difficult to do so. There are several reasons for the different findings. Tong's study was published over 10 years ago; since then, surgical techniques have improved with a decrease in postsurgical mortalities and morbidities (Leblanc, 2009). The question at hand is whether this has led to a change in the ways both parents and health care practitioners talk to teens about their CHD. Is there a greater emphasis today on telling these teens that they are normal? And if so, how does this shift in perspective affect them? Their physical activity levels are different, and they will need specialized care as they grow older. If they perceive themselves as normal, will their health suffer once they are on their own without supervision from parents and their pediatric specialists? Or will these teens continue to take their health issues in stride, further incorporating their CHD into their lives as they see fit?

Physical Activity

Quality of life is affected by an individual's ability to participate in physical activities. Physical functioning was the one thing that set the teens in this study apart from their peers. It is logical to suppose their quality of life would be

affected, although this was not measured in this study. In a study of adult patients with CHD, Loup et al. (2009) found that the adults adapted by avoiding physical activities that made their symptoms increase and therefore did not feel that their quality of life was affected. In a study of how self-reported exercise capacity in adults and adolescents with CHD related to their actual exercise capacity, Gratz et al. (2009) found that the two groups were poor reporters of their exercise capacity. They claimed that one should "Never trust a patient pretending a good exercise capacity" (p. 503). The knowledge deficit regarding their CHD diagnosis and sequelae may lead to parental overprotectiveness and over- or underexertion on the part of the teens and adults, which in turn can lead to false reporting. Failing to understand how teens communicate about issues such as physical activity and perhaps more importantly the background surrounding their involvement or lack thereof in these activities may have a detrimental effect on their overall health and quality of life.

CHD as a Foreground or a Background Issue

As teens with CHD mature, they need to move into the world of adult health care, which creates opportunities for their increased independence. As part of this process, understanding the risks (or benefits) of making choices about CHD being in the background or foreground is key to them making decisions that best affect their health. As was developmentally appropriate, the teens in this study wanted to become more involved with choices about their health care. Effective transition programs contain components of choice. Creation of a program that involves a transition of care as opposed to a transfer of care from one specialty group to another is most beneficial to all involved in the care of teens with CHD (i.e., the teens themselves, their parents, and their health care practitioners; Betz, 2004; Moons et al., 2009).

Expressions of denial and control were central issues in the illness narratives of adolescents in treatment for cancer (Kameny & Bearison, 1999), and thus one might argue that the descriptions of putting CHD in the background that the teens in this study provided exemplified disengagement coping (e.g., denial, avoidance, or wishful thinking; Compas et al., 2006). Given the study teens' ability to view themselves as normal, we assert that they provided examples of secondary control engagement coping, cognitive restructuring in particular (Compas et al., 2006). Research with adolescents with recurrent abdominal pain demonstrated that secondary control engagement coping predicted lower levels of anxiety/depression symptoms and somatic complaints, and disengagement coping was related to higher levels of anxiety/depression and somatic complaints (Compas et al., 2006). Similarly, in a study of adolescents with diabetes, the use of primary control coping strategies (e.g., problem solving, emotional expression) was associated with higher competence scores, better quality of life, and better metabolic control. Secondary control coping strategies (e.g., acceptance, distraction) were related to higher social competence,

better quality of life, and better metabolic control and disengagement coping strategies (e.g., withdrawal or denial) were linked with lower competence and poorer metabolic control (Jaser & White, 2011). Assisting teens to be self-aware of when they are situating their CHD in the foreground or background and to understand this as an effective coping strategy, especially in relation to their physical limitations, can facilitate effective self-management of their CHD within their everyday life.

Limitations

Several potential limitations are of note. Firstly, the teens interviewed did not all have the same CHD leading to differences in both their medical and surgical histories (and futures) and therefore differences in how their quality of life was affected by their overall condition. Secondly, all interviews were not conducted by the same interviewer, which may have resulted in different approaches to the questioning and the direction the interview took. In an effort to address this limitation, multiple research team members contributed to data analysis and interpretation. Several measures were taken to address this potential limitation. Consistent guiding questions were used for each interview and whether the same or different interviewer conducted the subsequent interview, interview recordings, and transcripts were reviewed, and questions to clarify or amplify data from the previous interview were prepared for the interview. The first author took the lead in data analysis and interpretation and met regularly with the research team to discuss findings and seek confirmation of the direction of her interpretations.

Implications

There are several areas that require further research. Recognition of the parent's point of view can augment our overall understanding of teen's perspectives and merits further research especially as we move to intervention research that includes both the teens and their parents. Further research with the data collected from the PedsQL will be analyzed to identify whether it reflects what teens reported in the interviews. Lastly, further investigation into quality-of-life concepts is necessary to better understand what quality of life is for teens with CHD and what it is not and the degree to which being different from their peers determines their quality of life. The dimensions that encompass quality of life (such as psychosocial, physical, emotional) are varied, and their inclusion or exclusion from a quality-of-life tool is not always apparent.

Conclusion

Teens growing up with CHD are in many ways similar to their peers. The fact that they have a congenital heart defect

has set them apart from their peers and therefore has created a situation whereby a need to feel normal is often heightened. Fitting in with peer groups is important to this group. A discussion surrounding the issues that enable a teen to feel like they fit in (such as grades, scars, employment, and physical activity) will create opportunities for health care practitioners to address quality-of-life issues. Deciding when to play their CHD (card) and when to move their CHD to the foreground or background of their lives has enabled these teens to best cope with the obstacles they have encountered. In a discussion about quality of life with teens, understanding this concept is foremost if one is to get at the core of the issues at hand.

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Guiding Questions

First Interview

What's a typical day like for you right now? [Warm up question. Probes: What kinds of things do you enjoy doing? Sports/after-school activities/babysitting? How's school? Do you enjoy your friends? How are things in your family? Are you easy to live with?]

On a typical day what sorts of things do you do that might set you apart from your friends? Do you think this is related to your heart condition? Tell me how? [Probe: ?Restrictions: Diet /activity/meds]

What has it been like growing up with CHD? [Probes: Teens growing up with CHD have been described as having a life that is "not ordinary.". How would you respond to that description? What does an ordinary life look like to you?]

What has been the best thing about growing up with CHD?

What has been the worst/hardest thing about growing up with CHD?

Anything else you'd like to tell me about growing up with CHD? What has it been like to talk with me about growing up with CHD?

Subsequent Interviews

Anything new since we met last – appointments, changes in teen's health, medications?

Questions to clarify or amplify data from first interview.

Tell me about filling out the quality of life questionnaire. Did you find the questions easy to answer? Do you feel that they were relevant to you in terms of asking about problems or concerns you may have with your heart condition?

Do you think these questions reflect what your idea of quality of life is? Is there anything that's missing?

In your own words, can you describe what quality of life means?
Were there problems or concerns that you have that you found
weren't addressed in this questionnaire? Tell me about them.

Anything else you'd like to tell me about your CHD? What has it
been like to talk with me about your CHD?

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