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Quality of Life in Adolescents with Congenital Heart Disease

by

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Dedication

This thesis is dedicated to you Tom. Your love, encouragement, and constant support have held me up and kept me pushing forwards.

Abstract

Technological advances for treatment of congenital heart disease (CHD) have led to decreases in mortality over the past thirty years. Persistent morbidity into adolescence and adulthood necessitates regular medical follow-up and the influence of ongoing physical health issues on the teens emotional health merits clinician and researcher attention. Employing interpretive description research methodology, 22 interviews with teens aged 13-17 years were analyzed to understand how adolescents with CHD describe everyday life and relate to questions about quality of life (QOL). Although the majority of these teens viewed themselves as normal, CHD was a part of their everyday life that they situated into the foreground or background of their lives, as it suited their needs. These teens spoke of QOL issues in a concrete manner focusing on physical activity limitations and their need to fit in. Further discussion of these issues must be undertaken as adolescents with CHD transition to adulthood.

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CHAPTER ONE

Introduction

Those suffering from congenital heart disease (CHD) now live well past childhood and even into adulthood (Moons, Budts & De Geest, 2006) as a result of technological advances in pediatric cardiology. Each year in the United States alone, 40,000 newborns are affected by CHD (Connolly, Rutkowski, Auslender & Artman, 2002). Up to 90% of these newborns (Claessens et al., 2005) will thrive and survive into adulthood, thereby increasing the need for appropriate and specialized health care services for this emerging population of adults with CHD (Canobbio, 2001). These individuals are viewed as unique in the medical world and as they move forward with their lives, their parents and health care practitioners alike face new challenges. The uncertainty about present and future outcomes that has characterized the lives of many of these children with CHD does not lessen as the adolescent faces adulthood. In fact parents must face the realization that their children are pushing for independence in all aspects of their lives and acknowledge the influence of this on their teen's heart health. Health care providers, for their part, are dealing with a new population of patients with distinct issues that many practitioners have not previously seen.

Despite remarkable advancements in pediatric cardiology and more recently in adult congenital heart services, there remain considerable morbidities for adolescents with CHD that must be addressed as they anticipate adulthood. A specialized plan of care that addresses the needs of teens transitioning into adulthood is necessary due to continued cardiac care beyond adolescence (Somerville, 1997). According to Somerville, the main causes for hospital readmission in grown-ups with CHD are: arrhythmias, the most common being atrial flutter and fibrillation; heart failure; pulmonary vascular disease; endocarditis; and reoperation for congenital aortic valve disease and secondary atrial septal defects. A continued need for anti-coagulant therapy is also an important component of care that is often overlooked (Somerville). Along with continued cardiac health support, this population of teens with CHD also needs non-cardiac health care services (Canobbio, 2001). In her discussion of transition related health concepts, Canobbio points out several of the issues facing teens regarding their reproductive health. Concepts such as sexuality, contraception use, genetic transmission and pregnancy risks all need to be a part of transition planning.

Given the persistent health concerns for adolescents and young adults who have survived their CHD, it is not surprising that quality of life issues have received increased attention (Macran et al., 2006). There is concern however that the adolescent's perspective is not being sought directly (McMurray et al., 2001; Pike et al., 2007). 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 as a proxy of the teen's quality of life (Gratz, Hess, & Hager, 2009; Sparacino et al., 1997). Direct measures to quantify the quality of the lives of teens living with CHD have been developed (Macran et al., 2006; Uzark, Jones, Burwinkle, and Varni, 2003; Varni, Seid & Rode, 1999) and studies utilizing these measures are appearing in the literature. For example Macran et al. developed the ConQuol, a questionnaire which measures the health-related quality of life (HRQOL) of children (aged 8-11) and teens (aged 12-16) who have grown up with CHD. Varni et al. developed the PedsQL, which also measures the HRQOL of children and teens who have grown up with a chronic illness and Uzark et al. developed the cardiac module for the generic PedsQL

Qualitative methods have also been employed to directly study the quality of life for adolescents (Kools, Gilliss, & Tong, 1999; McMurray et al., 2001; Tong, et al., 1998). The focus of this past research, both quantitative and qualitative has been on the cardiac aspects of these teens' lives (e.g., hospitalization, limitations related to CHD). The teen voice however concerning their perspectives on and reflections of their everyday lives living with CHD seem to be missing. As quality of life is a concept that potentially encompasses all facets of one's life, it therefore seems prudent to endeavour to understand how CHD intertwines itself into the everydayness of being a teenager with this condition.

Growing up with a large immediate and extended family, participation in various community clubs and groups with teens and young adults, as well as my direct nursing work with teenagers on a pediatric surgery unit are all encounters that have enabled me to gain considerable and valuable experience relating to teenagers. Specifically my work on a pediatric inpatient unit has afforded me opportunities to interact with a diverse group of teenagers living with chronic illnesses who are at various stages of their development. These experiences (and my own personal experiences as a teen) have aided in my understanding of how teenagers both think and act and to appreciate that getting teens to answer questions and talk about even their day-to-day life, much less their health concerns, is not straightforward. As teens with chronic health conditions, including CHD, struggle to gain independence in their lives, they must also struggle with the reality that their lives are different from those of their healthy peers and that their futures will be different as well. As clinicians, we seek to lessen the struggle with regards to the health care needs of the teens, but in so doing, often miss the mark or neglect to see what really is at issue for these teens. An understanding of what life is like for teens with CHD is essential to providing appropriate services but also to ensure all the health care needs of these unique individuals are being met.

Purpose of the Study

The purpose of this study is to understand how adolescents with CHD describe their everyday life and relate to questions about the quality of their life. The research question guiding this study is: how does CHD affect the everyday life of adolescents?

Significance of the Proposed Study

In his analysis of the concept of QOL, Meeberg (1993) noted that there are various dimensions attributed to quality of life such as: general life satisfaction; individual mental competence that allows one to adequately assess life satisfaction; the ability to individually determine that one has a satisfactory state of health; and finally that the individual's living conditions have been assessed by an impartial individual, and that these living conditions have been deemed adequate. The notion that different value is placed on different dimensions of quality of life is of relevance as it helps explain why it is important to identify what different individuals see as important aspects in their quality of life. Eliciting qualitative data through an interactive interview about the youth's day-to-day life and perceptions of CHD as well as asking questions about the experience of filling out a questionnaire on quality of life helped me to discern whether or not the issues raised in a QOL of life questionnaire were actually relevant to the lives of adolescents with CHD. Discovering how adolescents with CHD assign meaning and relevance to this process was thus achievable.

Adolescence can be a trying time without the addition of a chronic illness. Most teenagers are searching for independence and looking to break free from the tightly held reins their parents have kept on them. An adolescent with CHD is no different from his peers in this respect; the difference is that he or she may have a more difficult time reaching this state of independence due to overprotective parents, not to mention his or her own fears of setting out on their own. To discover how adolescents with CHD identify with these various issues, further study must be undertaken. Exploring quality of life issues such as ways in which adolescents attach meaning to their unique situation, their inability to partake in many competitive sports, their uncertain futures, and their need to take a variety of medications, is one way to address to these concerns. Perhaps what an adolescent indicates is significant to their quality of life, is vastly different from what a questionnaire conveys and also different from what their parents believe is important and relevant in the lives of their children. Making the effort to recognize and appreciate this different standpoint will help parents, nurses and all others involved in the transitioning phase to address what really matters to the adolescents with CHD.

CHAPTER TWO

Literature Review

Through a review of the literature concerning adolescents, CHD and quality of life four themes pertaining to the study of QOL issues were identified: psychosocial concerns, physiological concerns, knowledge concerns and the importance of addressing the unique adolescent perspective. The literature reviewed will be discussed in terms of these themes and gaps identified therein, as it is argued that QOL for adolescents in pediatric cardiology is relevant and deserving of further research. The concept of transition is also explored within this review to show how it features within a discussion of QOL issues. Finally, the strengths and limitations of the various articles are discussed in terms of their contributions to this developing field of interest.

In the review of the literature, a preliminary search using the following search terms was conducted: congenital heart disease, adolescents, and quality of life. These terms were used together and separately to amass literature pertaining to each of the subject headings. The reference lists from these articles were studied and further articles were found, many of which were published in the nineties exemplifying that recent relevant research is lacking. This was a disconcerting finding given the repeatedly documented clinical concerns for the emerging population of adolescents with CHD that will require life-long medical care; conversely, it was reassuring to know that the proposed research had not been previously done.

Of the 24 articles found, six were reviews of the current literature pertaining to QOL (Ferrans & Powers, 1985; Latal, Helfricht, Fischer, Bauersfeld, & Landoldt, 2009; Meeberg, 1993; Moons et al., 2006; Moons, Van Deyk, Budts, & De Geest, 2004; Pike et al., 2007) of which only three focused specifically on quality of life in CHD patients (Latal et al., 2009; Moons et al., 2004; Pike et al., 2007); two review articles focused only on outcomes and management of CHD (Cohen, 1992; Green, 2004); and five focused on clinical issues such as transition and strategies for helping teenaged CHD patients and parents through this phase of life (Betz, 2007; Canobbio, 2001; Higgins & Tong, 2003; Knauth, Verstappen, Reiss, & Webb, 2006; Tong & Kools, 2004). Of the 11 qualitative articles found, there were only four studies done where the specific adolescent (13-17 years) perspective was sought (Berntsson, Berg, Brydolf & Hellstrom, 2007; Kyngas, 2003; McMurray et al., 2001; Tong et al., 1998). The Kyngas article did not include CHD patients in the subset but was included because of its relevance with regards to the adolescent perspective. Seven of the articles pertained to quantitative research undertaken with teens with CHD and in this grouping, the adolescent perspective was represented, but four of the seven pertained to the development of a QOL tool/index (Connolly et al., 2002; Macran, et al., 2006; Uzark et al., 2003; Varni et al., 1999) and did not report study findings related to the QOL of adolescents.

The majority of the research related to teenagers growing up with CHD comes from the same two groups of individuals - Moons and his colleagues at the University Hospitals of Leuven, Belgium (Claessens et al., 2005; Moons et al., 2006; Moons et al., 2004; Van Deyk et al., 2007) and Tong and colleagues from the Department of Family Health Care Nursing, University of California, San Francisco (Higgins & Tong, 2003; Kools et al., 1999; Sparacino et al., 1997; Tong et al., 1998). Some of these articles were theoretical as well, focusing on conceptualizations of quality of life (Moons et al., 2006; Moons et al., 2004). From this review it was evident there was a lack of research undertaken that focused purposely on the QOL issues in teens with CHD. There were however several common themes that occurred throughout the articles which will now be discussed.

Psychosocial Concerns

In the literature, several key psychosocial issues have been identified for teens who have survived their life-threatening congenital heart disease and grown up with CHD. In a qualitative study of 37 adolescents aged eleven to eighteen years old, McMurray et al. (2001) identified five themes. They found that the adolescents' "less ordinary life" stemmed from issues of coping, limitations, exclusion, discrimination and bullying, and hope for life improvement. The young adults in this study spoke about their "embarrassment of being left behind" (p. 54) due to their physical impediments and that this in turn led to exclusion by others, which "still had the potential to cause anger and upset" (McMurray et al., p. 53). They concluded that greater attention to the psychosocial needs of adolescents with CHD is necessary. A strength of this study is rooted in the authors' focus on the adolescent specific perspective. These authors did not however address the concept of quality of life, focusing instead solely on the *experience* of living with CHD, a concept which requires further development to understand how it relates to quality of life.

Kools et al. (1999) conducted a qualitative study with a group eight patients, aged 22-40 years old, all affected by CHD. Family members, pediatric nurses and adult nurses were also involved in this study which identified the unique psychosocial needs of hospitalized CHD patients and their families. The young adults in this study found their level of dependency met with differing responses from the nurses. The pediatric nurses accustomed to a dependence type relationship were not as comfortable including the young adults with CHD actively in their treatment. The adult nurses on the other hand perceived the dependency relationship between young adults with CHD and their parents as dysfunctional (Kools et al). These differences of opinion among the various groups of health care providers can be expected given the different approaches used in the two settings (pediatric versus adult). The medical and surgical histories of these patients seemed not to be recognized by the nurses which led to a lack of understanding of how best to provide care for these patients, resulting in conflict and tension between patients, families and nurses. Overall dissatisfaction with care as expressed by the patient and family members' resulted.

Tong et al. (1998) conducted an exploratory descriptive qualitative study with nine adolescents and young adults aged 13-25 years old, to understand the dilemmas and challenges they and their parents experienced in relation to their CHD. The authors identified several themes that were psychosocial in nature including: dilemmas of normality, of disclosure, and of finding strategies for illness management; challenges of social integration versus social isolation; of dependence versus independence; and finally, the challenge of uncertainty. Developing strategies for coping was also highlighted as a psychosocial issue facing these adolescents as they matured. Tong et al. discussed how "these adolescents and young adults were grappling with the critical dilemma of perceiving themselves as either 'normal', 'equal to and like everyone else' or 'different', deficient and less than perfect, and thus at risk for being an outsider" (p. 308). The psychosocial concerns of adolescents with CHD are significant and need to be taken into consideration as low self esteem, anxiety, and depression were identified as major issues for this group of individuals (Tong et al., 1998).

Claessens et al. (2005) examined the lived experience of adult patients with CHD to outline the need to understand the influence CHD has on the lives of young adults with CHD and so that practitioners are better prepared to promote a positive quality of life. Claessens et al. found that the feeling of being different was predominant among the young adults in their subset and consequently they (the young adults) struggled constantly to achieve a sense of normalcy in their lives. Similarly, both Canobbio (2001), in her discussion of health care issues facing teens with CHD and Somerville (1997), in her article concerning the management of adults with CHD point out that practitioners have a responsibility to ensure that individuals with CHD are able to achieve a quality of life similar to that of their peers and as such must be prepared to help these patients address psychosocial issues as they progress through life.

Physical Concerns

Research conducted with adolescents with CHD highlight the concerns that these teens have concerning their physical bodies. Adolescents have described physical characteristics that visually set them apart from their peers; cyanotic lips, small stature, and surgical scars (Tong et al., 1998). McMurray and colleagues (2001) also found that adolescents with CHD defined many of their problems in terms of impairment. In other words, the adolescents in this study claimed that their social exclusion was due in large part to their physical characteristics, for example, decreased stamina and limited ability to keep up (McMurray et al.). Other physical characteristics found to be 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 activities such as physical education, after school sports teams, horseback riding, bicycling, and scuba diving (McMurray et al., 2001; Tong et al., 1998). In a small study on young adults and adolescents, Tong et al., found that when it came to participation in sports, it was the males who found it particularly difficult to cope and that they were more sensitive to this constraint than their female counterparts.

Males also experienced difficulty coping with the idea that their decreased physical abilities would affect their career choices and body image. Both McMurray et al. (2001) and Tong et al. (1998) discussed how the physical attributes characteristic of these adolescents effectively removed some life choices such as smoking or choosing a job that entailed manual labour. One of the adolescents did not go out to the pubs with her friends due to her need for increased caution (McMurray et al.). This young woman commented that they (her friends) "don't have a problem with that (going to pubs) but occasionally I do" (McMurray et al., 1998, p. 54). The regular day-to-day activities that adolescents take for granted become off limits to many of the adolescents with CHD, thus leading to increased feelings of social exclusion. Missing from the literature was any direct reference on whether or not these feelings of exclusion were even considered by teens to be a factor in their QOL and how in turn the quality of their life was affected by the latter.

Knowledge Concerns

In a descriptive, cross-sectional research study of 54 adolescents with CHD (Van Deyk et al., 2007), it was found that adolescents had significant gaps in their knowledge base about how CHD was affecting their lives. For example, less than 50% of respondents were able to correctly name their heart defect, their follow up needs, their medication plans, and the symptoms that would indicate a worsening of their heart condition. An effort to comprehend the problems adolescents with CHD will confront over time benefits the adolescents' and their families as the former mature and become responsible for their own health care. Given that quality of life is affected by physical health status, endeavouring to identify and explain these key concerns is necessary to understand how quality of life features meaningfully within the context of adolescents' lives.

Quality of Life

The concept of quality of life (QOL) is being studied with increasing frequency in health care and QOL concepts are now often being examined with patients as the benefits of different treatment options are discussed (Moons et al., 2006). The same is true about regarding QOL of CHD patients as evidenced by the increase of studies and reviews related to this topic (Latal et al., 2009; Loup et al., 2009; Macran et al., 2006; Eiser, Mohay, & Morse, 2000). As Addington-Hall and Kalra (2001) point out, the impact of a disease or illness on a patient's life and not just on the patient's body must be understood. In the case of teens growing up with CHD, this is no different and a better understanding of QOL will help ensure a greater understanding of how patients' lives are affected by CHD. Addington-Hall and Kalra state that QOL tools measure subjective experiences and as such a QOL tool measuring CHD in this population should be reflective of these (subjective) experiences.

Moons et al. (2006), in their review of the QOL literature in pediatric cardiology discussed their concern that consensus has not yet been reached concerning the exact determinants of QOL. This can lead to problems when trying to decide on a tool to measure quality of life and in fact the above authors question whether or not QOL can be measured. Moons et al. has provided leadership in the area of QOL by helping to develop a conceptual definition whereby QOL is best defined 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). Another way of saying this would be that QOL should not be measured only in terms of the presence or absence of symptoms. Research protocols need to be designed that elicit the teen’s perspective about all aspects of their life, not just concerning their CHD. Conceptual definitions add to the growing body of literature regarding adolescents with CHD, however more work needs to be carried out to determine if the definition put forth by Moons et al. (2006) is appropriate for adolescents outside of their study.

In their work with adult palliative patients, Cohen and Leis (2002) developed a definition of quality of life that has relevance for adolescents with CHD. After completing interviews with the terminally ill adult patients, Cohen and Leis concluded that quality of life is a subjective view of wellbeing. Through their application of the McGill Quality of Life (MQOL) questionnaire, these authors found that due to the inherent subjectivity of QOL, the contributing factors influencing “quality of life are best defined by members of the group for whom the quality of life measure is designed” (Cohen & Leis, 2002, p. 48). It follows then that researchers in pediatric cardiology could elicit QOL data directly from adolescents either in the course of an interview or by having the teens filling out quality of life questionnaires rather than relying on parents’ data concerning their teen’s QOL.

From the review of the literature, in only four studies were data elicited from the teens directly (Berntsson et al, 2007; Kyngas, 2003; McMurray et al., 2001 and Van Deyk et al., 2007). Of those four articles, it was only the latter two that focused exclusively on teens and their specific thoughts, concerns and understanding of growing up with CHD; McMurray et al. examined issues teens faced around growing up and coping with CHD, while Van Deyk et al. focused exclusively teens' understanding of their CHD. The remaining 14 articles reported on the findings of studies that included either children only (Davis et al., 2007; Eiser et al., 2000); a mix of children and teens (Connolly et al., 2002; Macran et al., 2006; Uzark et al., 2003; Varni et al., 1999); a mix of teens and adults (Sparacino et al., 1997; Tong et al., 1998); or adults only (Claessens et al., 2005; Cohen & Leis, 2002; Kools et al., 1999; Loup et al., 2009). The study undertaken by Sparacino et al. represented the opinion of only the parents of teens and young adults with CHD, a perspective that is important but nevertheless fails to elicit the adolescent specific point of view, which when examined can contribute to more comprehensively addressing the health care needs of this unique population. From this summary of the literature I reviewed, it is evident that there remains a scarcity of data reflecting the views and opinions of the teens themselves, relating to QOL issues. It is therefore important to ensure that the questions about quality of life are appropriate and relevant and identify what the adolescents deem as key contributors to their quality of life. This is why the study proposed will strive to understand how adolescents with CHD describe their everyday life and relate to questions about the quality of their life.

QOL thus encompasses many aspects of one's life, not just the psychosocial and physical features. In reviews of pediatric cardiology literature both Green (2004) and

Pike et al. (2007) found that limited research had been done on the quality of life in CHD patients, especially as it related to social functioning and overall wellbeing. The existing research on quality of life in adolescents with CHD under represented the adolescents' point of view. In the Connolly et al. (2002) study only 14 of the 92 participants, who ranged in age from six months to 20 years, were teens and the parents' perceptions of their child's quality of life was often different from their child's report. Considering quality of life and how it relates to adolescents living with CHD is essential to facilitating their successful transition from adolescence to adulthood.

The Adolescent Perspective

Connolly et al. state that further research is necessary to clarify the teen perspective on quality of life as "adolescents with heart disease may perceive themselves to have a better quality of life than that perceived by their parents" (p. 79). In a recent systematic review of the literature related to long-term outcomes in the CHD population, Latal et al. (2009) pointed out that QOL "impairments are more frequently reported by parents than by the patients themselves (p. 12)," a point supported by my own review of the pertinent literature. A lack of quality of life assessment tools designed specifically for adolescents was identified by Connolly et al. (2002) as one possible contributing factor and so this group undertook the task of developing a tool, a process described in their article. In fact several of these same studies point out the fact that there are differing viewpoints brought up by parents and adolescents in terms of how each group considers quality of life. For example, Connolly et al. argue that children and teens at times have a point of view contrary to their parents when it comes to the issues regarding symptoms of the disease, thus leading to erroneous perceptions about overall QOL. Alternatively, Eiser et al. (2000) propose that parents are better situated to respond to questions about their children’s quality of life because their children’s cognitive maturity is not yet fully developed, they (the children) have had limited social experiences, and they continue to depend heavily on their parents. These authors argue then that in some respects, children are not mature enough to reflect on what quality of life really means and so who better than parents to provide the answers. This has been referred to as the “parent-proxy” (Pike et al., 2001) whereby the subjective opinion of the parents is measured as it pertains to the subjective experiences of their children.

Uzark et al. (2003) developed a cardiac module to be administered with the already established PedsQL quality of life survey (Varni et al., 1999), a process undertaken in order to address the specific teen point of view. These authors feel that the impact of CHD on youth has not been studied to its full extent and thus requires a special measure that addresses the unique aspects of these participants’ lives. It is used in conjunction with the PedsQL, a generic tool that assesses both parent’s and children’s health related quality of life (Varni et al., 1999). The generic module focuses on questions that concern health and physical activities, feelings and emotions, how well the adolescent gets along with others and how they manage at school. The cardiac module has a distinctly more health oriented approach focusing on dimensions such as heart problems and treatment, medication use, perceived physical appearance, treatment problems, cognitive problems and communicative abilities (with the latter four categories pertaining specifically to the adolescents health care concerns).

Uzark et al. administered the tool to 250 children with CHD aged five to eighteen and 344 parents of children and teens with CHD and found that the results supported feasibility, reliability and validity of the PedsQL. Uzark et al. are interested in collecting data from both parents along with their children as circumstances may arise where a child or teen is unable to fill out the questionnaire however the authors recognize that parent data may not be sufficient when decisions are being made about future treatments for the child or teen.

Davis et al. (2007) conducted qualitative research with 15 healthy adult-child (children were aged 8-12 years) pairs in an effort to understand why children and parents answer surveys differently. They found that the differences could be attributed to variations in reasoning, in response styles and in interpretation of the questions thus emphasizing the need to elicit responses from both parents and (in this case) adolescents in order to obtain data that is relevant to furthering knowledge about the influence of CHD in the lives of teens and their families. Pike et al. (2007) point out that examining the perspective of adolescents with CHD “could provide insight into potential health, psychological, or social concerns not identified by parents and give voice to help others” (p. 14).

McMurray et al. (2001) draw attention to the fact that studies involving adolescents with CHD have tended to be based on objective physiological (e.g., treadmill testing) and psychological testing, thus leaving out the important concept of quality of life. Attending to the unique perspective of adolescents through qualitative interviews themselves will contribute to a more complete description of their lives, thus facilitating a necessary understanding of what it means to transition from adolescence to adulthood. The issues important to these young people may differ from those important to their parents and health care practitioners and soliciting this information could be potentially helpful. Mortality rates have decreased over the years as medical and surgical advances have improved. It is important not to lose sight of the ultimate goal of health, which according to the World Health Organization (2006), is not merely the absence of disease. Quality of life is in part achieved when physical, mental and social health issues are attended to. For this reason, focusing on quality of life issues for adolescents with CHD is important.

Summary of Literature Review

Strengths

The concept of quality of life is gaining importance in health care. In reviewing the literature, support for this view is increasing in breadth and depth, thus further indicating the value of undertaking a study investigating this concept. Quality of life has been redefined and reworked in an effort to derive a conceptualization that reflects the multifactorial components of living with a chronic illness. Literature on the specific case of patient's with congenital heart disease and their special circumstances is growing (Connolly, et al.; 2002; Green, 2004; Macran et al., 2006; Pike, et al., 2007). There is recognition of the benefit in considering both the parent's and the adolescent's points of view (Connolly et al., 2002; Macran et al., 2006; McMurray et al., 2001; Pike et al., 2007; Tong et al., 1998). Attempts have been made to develop scales or assessment tools such as the ConQuol (Macran et al.,) or the PedsQL (Varni et al., 1999) and PedsQL Cardiology module (Uzark et al., 2003) that pertain directly to pediatric CHD patients. By constructing and utilizing instruments developed for a specific population, data will be more focused on issues relevant to the group.

Limitations

I identified several limitations through my literature review. Firstly, there remains little research pertaining to the unique situation of the adolescent patient with CHD. This population sub-group is distinctive in that adolescents are dealing with normal, transitional, independence seeking issues, along with learning to increase personal responsibility for their health management. Although the parents' perspective with regards to their teen's QOL issues has a place in knowledge development in pediatric cardiology, I have argued through my literature review for the importance of including the adolescents' point of view. McMurray et al. (2001) specifically mention that there are few studies pertaining to views of adolescents with CHD. Pike et al. (2007) indicate that the focus has been on the views of family members rather than the specific adolescent opinion as it correlates to their health-related quality of life.

Of note as well, is the observation that QOL measurement tools encompass many different areas of one's life. The problem that can develop when quantifying overall quality of life is that the value people place on various dimensions of their life, likely differs from one person to the next thus contributing to different calculations of overall quality of life (Ferrans & Powers, 1985). Undertaking a study on QOL in the adolescent CHD patient population, which will be done in part through the use of a generic tool, the PedsQL, in conjunction with the cardiac module (Uzark et al., 2003) will help to address this concern by seeking to identify the unique adolescent perspective with regards to completing a QOL measure.

Transition

As adolescents with CHD move from the pediatric world of care into that of the adult world, a shift in focus occurs away from family centered care, to a focus on the patient as an individual. In the literature, this process has been referred to as the transition period, a stage within young adults with CHD and their parents often find themselves unprepared to enter (Betz, 2007; Canobbio, 2001; Knauth et al., 2006; Kools et al., 1999; Pike et al., 2007; Tong & Kools, 2004; Tong et al., 1998;). Some of the key elements that need to be discussed in the transition process revolve around medication management, arrhythmia considerations, residual hemodynamic conditions, employability, and future reproductive concerns (Knauth et al., 2006; Kools et al., 1999; Tong & Kools 2004). Kools and her colleagues (1999) emphasized the importance of teaching the adult patients about their illness so they would be well-positioned to make decisions about their future health care needs. The transition process, if well attuned to patient needs, can be of benefit to these adult patients, their families and their care givers. Most recently, Loup et al. (2009) further reiterated this point in their QOL study where they found that a multidisciplinary approach to the care of grown-ups with CHD was necessary for the overall management of their care. This is an area for future research but is beyond the scope of this study.

Conclusion

Several key themes were introduced that pertain to the literature surrounding congenital heart disease in the adolescent population. Issues and concerns surrounding the transition phase, psychosocial and physiological problems, quality of life and the adolescent perspective were discussed in detail to determine the current state of research on this subject. The viewpoint held by parents with regards to quality of life issues, has been examined and discussed. The adolescent point of view has not been studied in great detail, nor have questions been asked with regards to whether or not the latter feel that the quality of life questionnaires are useful tools that reflect their own concerns. As providers of holistic care for their patients, nurses are in an excellent position to both gather and disseminate the knowledge that can be gained from further exploration of the concepts such as transition and QOL.

CHAPTER THREE

Methodology

Although a method for objectively quantifying QOL of teens with CHD has been developed (the PedsQL and accompanying cardiac module) and could be used in quantitative research with large numbers of teens to establish quality of life outcomes for teens who have survived their CHD, for my thesis research, I opted to take a step back to ascertain if teens with CHD relate to questions about the *quality* of their life, and if so, how they describe their everyday life and its relation with the quality of their life. My aim herein was not to develop a new theory on this subject of interest. Alternatively, as Thorne (2008) points out, there is a need to include "knowledge pertaining to the subjective, experiential, tacit, and patterned aspects of human health experience" (p. 36) and so expanding clinicians' knowledge base on issues related to QOL in teens is both relevant and appropriate.

To comprehend what life is like for youth living with CHD, specifically in terms of the concept of quality of life, I endeavoured to ascertain whether or not adolescents with congenital heart disease could describe their everyday life and relate to questions about the quality of their life. The qualitative research framework of interpretive description (Thorne, 2008) guided my inquiry. This qualitative method is described and examined with respect to sampling, data collection, data analysis, issues surrounding rigour, followed up with a brief discussion of the ethical considerations undertaken.

Interpretive Description

Interpretive description was first introduced in the late nineties by Thorne, Reimer Kirkham and MacDonald-Emes (1997). It was presented as an alternative method of doing qualitative research that did not rely on the traditional research methods of grounded theory, ethnography and phenomenology that are rooted in disciplines other than nursing. Thorne et al. (1997) put forth the notion that interpretive descriptions "represent the foundation for nursing's theoretical structure and its substantive body of knowledge" (p. 173). The philosophical underpinnings present in most qualitative methodologies are also apparent in interpretive description. This methodology aligns itself within the realm of interpretive naturalistic orientations (Thorne et al.) and maintains the three philosophical tenets put forth by Lincoln and Guba (1985, as cited in Thorne, Reimer Kirkham, & O'Flynn-Magee, 2004). These three points focus on the idea that when using naturalistic inquiry, "there is no pre-selection of variables to study, no manipulation of variables, and no a priori commitment to any one theoretical view of a target phenomenon" (p. 337). Although QOL was chosen a guiding concept in this study, it was in no way a variable that could have been manipulated and in fact we sought to understand how QOL as a concept featured in the day-to-day lives of the teens interviewed. It can therefore be said that QOL was a concept we sought to better understand, rather than a variable to be manipulated or a relationship among variables that we sought to investigate. The three philosophical tenets can therefore be said to have been upheld.

Interpretive description is a distinct methodology which offers an opportunity to better understand a nursing specific approach to caring for individuals with health care needs. As Thorne (2008) points out, "nursing always and inherently requires knowledge about patterns and themes within people in general so that it can better inform the care of the unique and distinct individual" (p. 25). As nurses seek to build their own distinct body of knowledge, the application of a methodology which seeks to validate this clear-cut point of view seems logical. Thorne underscores this reality when she points out that the lives of real people in the health care setting are affected by an application of this new evidence. This is no exception in the case of teens with CHD who must come to terms with the fact that they are in many ways different from their peers and as such will have health care needs that differ from the norm. To grasp what these needs are, one must have an understanding of how these teens view and relate to issues of quality of life. Research generated evidence is then available to guide health care practitioners' practice that addresses the physical, emotional or psychological needs of clients and their families. Interpretive description is well suited to meet these goals.

A qualitative research methodology such as interpretive description enables the researcher to do more than highlight and list phenomena discovered; relationships between phenomena can be explored and delineated (Sandelowski & Barroso, 2003). Thus, in this study, interpretive description enabled me to look beyond *what* constituted QOL for the teens and to focus on *how* and *why* different issues affected the latter individuals and therefore begin to comprehend what having a good QOL signified for them. In reviewing 62 qualitative studies Sandelowski and Barroso (2003) describe how an interpretive explanation may be able to bring to light the concerns of HIV positive women with respect to how each of these concerns was a “condition for distinctively different defensive strategies” (p. 914). The interpretive description methodology is compatible with the goal of generating clinically relevant data that health care practitioners can readily access as they continue to care for teens with CHD.

With interpretive description, themes and patterns are unearthed by studying the subjective perceptions of research participants, thus bringing up to date the clinical understanding of the phenomenon of interest (Thorne et al., 1997). Interviews were chosen as the method of choice for collecting data. As well participants were invited to complete the PedsQL questionnaire within the context of the interview. Using the QOL tool the PedsQL, my goal was to get at the subjective perceptions of the teen participants by asking them questions about what it was like to fill in the survey and to see if the activity itself enabled them to articulate their perceptions of QOL. In the proposed study, I examined concepts surrounding clinical health and illness phenomena, and as such found the interpretive description to be consistent with my aim to understand and clarify the day-to-day life of adolescents with congenital heart disease as well as their perceptions of their quality of life.

Sample and Recruitment

The target population in this study included youth between the ages of 13 and 17 years with CHD for which they had previous surgical intervention. Recruitment occurred through the Cardiac Sciences Program of the Stollery Children’s Hospital in Edmonton, Alberta and the two parent support networks in Alberta; The Children’s Heart Society serving Northern Alberta and Heart Beats which serves Southern Alberta. Inclusion criteria included the ability to read and speak English both for the purposes of participating in an interview and completing the questionnaires. Although our recruitment was aimed at the parents, our hope was that the teens of the parents who responded to our recruitment efforts would be willing to share their experiences of living with CHD as it pertained to their day-to-day life and their perceptions of their quality of life.

A key interest of the larger study was to assess the transition period from pediatric care to adult care for teens with CHD and we therefore recruited teens with CHD who would require ongoing monitoring of their condition into adulthood and therefore purposive sampling was utilized. According to Thorne (2008), this is a technique whereby “the settings and specific individuals within them are recruited by virtue of some angle of the experience that they might help us better understand” (p. 90). For this reason, participants had to have a congenital heart defect for which at this time there is no cure and for whom the disease would continue to be a part of their lives as they matured. In interpretive description a priori steadfastness to theory is avoided as the theory itself should emerge from the data as it is analyzed (Sandelowski, 2000), and indeed this was the case with this study. Although the concept of quality of life was identified as relevant based on the literature review, I was also open to this study being about something other than quality of life.

I had originally aimed for a sample of five to eight adolescents (between 13-17 years of age). Morse (2000) reported that a study that is broader in terms of scope or breadth of research will necessitate a larger number of participants, thus the opposite of this holds that a study such as mine that is narrow in focus and will therefore require fewer participants. Interpretive descriptions readily take into account what is already known about a specific area of interest and seek to use a variety of sources to increase the breadth and depth of the phenomena of interest (Thorne et al., 2004). Interviews are seen as a suitable method of data collection (Thorne et al., 2004) and as such were deemed to be appropriate for this study.

This study was undertaken within the context of a larger study investigating parenting adolescents with CHD. Parents contacted the project coordinator who provided further information about the study by telephone and through a mailed out information package. Parents approached their teens about participation in the study. If they were willing to participate, the project coordinator made arrangements with the parent and/or teen to meet for the first interview. In several cases, the teen was the one who saw the recruitment advertisement in the clinic setting and urged their parent to contact the project coordinator. Parents and teens were informed that the study included two interviews and that during the second interview a quality of life questionnaire would be completed and discussed.

Data Collection

Data was collected through interactive interviews with the teens apart from their parents. In total, one teen participated in one interview, six teens each participated in two interviews and three teens did three interviews. Additionally, teens were asked to fill out a quality of life questionnaire as an activity to elicit conversation about their quality of life. The questionnaire was given to participants during the second interview and was filled out in the interviewer’s presence. Although questionnaire data was collected during the interviews that provided the data for my study, the scores were not a source of data for my study. In her description of the different data sources available to the interpretive description researcher, Thorne (2008) points out that no one data source will suitably fulfill all research goals set out; each method available to a researcher, be it through interviews, participant observation or focus groups has its inherent strengths and limitations. Interpretive description “often involve[s] multiple data collections to avoid

… overemphasis on interview data" (Thorne et al., 2004, p. 5-6). By employing two different approaches to data collection, that is by way of a semi structured interview guide for the first interview and the activity of the completing the QOL questionnaire and by talking about the experience in the second interview, I hoped to capture how teens with CHD talked about and reflected on QOL issues.

The first interview was composed of open-ended questions aimed at eliciting the participant's descriptions of their everyday life in relation to living with CHD and their perceptions of their quality of life. The use of semi-structured interviews "[combines] the flexibility of the unstructured open-ended interview with the directionality and agenda of the survey instrument to produce focused, qualitative, textual data" (Schensul, Schensul, & LeCompte, 1999, p. 199). An interview guided in part by the answers provided by participants helped create a non-threatening environment where the adolescents were free to respond honestly and openly to the questions and the content and quality of the data gathered reflects this. An example question was "What's the best/worst thing about growing up with CHD?" Guiding questions for this interview facilitated the conversation and were aimed at their day-to-day activities, school work, extracurricular activities, friends, and family life (See Appendix A). The data collected and the ensuing relationships and themes constructed were revealed as seen through the lens of interpretive description.

Prior to the beginning of the first interview a demographics form was given to parents to fill out (See Appendix B). At the beginning of the second interview, the teens were asked to give the interviewer an update on their health status as well as to indicate whether or not they had had any appointments or procedures and whether there had been any changes to their medication regimes. From there, specific questions about their understanding of the term quality of life were sought, as well as their opinions surrounding the process of being interviewed.

During the second interview, participants were given the opportunity to fill out the PedsQL questionnaire and the PedsQL Cardiac Module (See Appendix C and D) (Uzark et al., 2003; and Varni et al., 1999), and a conversation then ensued to ascertain whether or not such a tool could be useful for youths with CHD as well as to discern whether or not it was a relevant way of identifying quality of life issues from the teen’s perspective.

Instructions on how to fill out the generic and cardiac PedsQL modules were given to the adolescents by the interviewer and the tape recorder was left on while the adolescent filled out the questionnaire. Several of the interviews were conducted over the phone and in these situations it was the interviewer who filled in the questionnaire as per the teens’ responses. As per the PedsQL Administration Guidelines (Varni et al., 1998), any queries that arose from the adolescent were not interpreted by the interviewer. The question was merely repeated back to the individual, they were asked to answer it as best they could, thereby providing an answer that best depicted their feelings regarding the subject matter. The questionnaires took approximately 10 minutes to complete and served as a point from which to elicit further descriptions of what the participants saw as being challenges they have encountered with respect to their chronic health problem.

The length of the interviews varied from approximately 45 minutes to a maximum of two hours. Interviews were done in the teen’s home although this was not always possible, as some participants lived out of the city or out of the province; the second and third choices were in the research offices or over the telephone. Of the 22 interviews conducted, five took place in the research offices, seven took place over the phone and ten took place in the participants' homes.

The PedsQL was used with the intended goal of adolescents feeling they could open up and share with the researcher their experience of daily life, living with CHD. More importantly however was the goal of having adolescents explain and reflect on their perceptions of their quality of life. We had hoped that the PedsQL would build the foundation from which questioning with regards to QOL could begin and that this in turn would lead to themes and patterns emerging which were "consistent with the reasoning of expert practitioners for whom a similar understanding had been acquired through extensive pattern recognition and reflective practice observations" (Thorne et al., 2004, p. 8). In so doing, we hoped the results would pass what Thorne et al. refer to as the "thoughtful clinician test" (p. 17) and as such ensure a high level of rigour in the study was achieved. Understanding the experiences of adolescents living with CHD and their perceived quality of life concerns will help clinicians work with this population of individuals and will help in the identification of concerns and issues pertinent to this unique group of young adults. This was an end the research team hoped to achieve through the use of both the open-ended questions and the use of the questionnaire activity.

Data Analysis

Data analysis within interpretive description is based on inductive reasoning rather than on deductive reasoning. Given this, Thorne et al. (2004) propose that jumping immediately into coding schemes will in fact hinder the researcher and promote the discovery of superficial findings. Rather, Thorne (2008) encourages researchers to fully immerse themselves in the data prior to beginning the process of coding. Listening to the interviews was thus the first step I undertook to immerse myself in the data. As Thorne et al. (2004) point out, “listening to an audio recording of a conversation may evoke a different insight than will reading a written transcript of text” (p. 14). Interpretation of the data was carried out through a process that involved listening to the electronic versions of the interviews and reading the interview transcripts, followed by the development of a coding scheme which was then applied to the interview data. It was thus through the process of moving in and out of the data that themes and patterns presented themselves in such a way as to permit the coding process to commence (Thorne et al., 2004).

For ease of interview data management, NVivo 7 was used for the project. This software program facilitates deep levels of analysis of rich descriptive information (QSR International, 2007) such as that obtained in this study. It also organized the data to make it accessible by other members of the research team. Transcribed interviews were proofed by a research assistant and then uploaded into NVivo 7. The proofing process involved reading the transcription while listening to the recorded interview to ensure accuracy. Any questions regarding the few portions of the interview that were not audible to the transcriber were referred to the person who conducted the interview. The PedsQL and cardiac module questionnaire data was not analyzed for the purposes of my study as it was not the aim of this study to elicit and analyze quantitative quality of life data. This data will be kept for future analysis by members of the research team. In the next section, I provide more specific details of the process I went through to allow me to engage with and begin to 'live in' the data.

Living in the data.

A major philosophical underpinning of interpretive description holds that theories about particular clinical phenomenon are not preconceived notions, but rather "must emerge from or be grounded in that phenomenon" (Thorne, 2008, p. 74). Using this approach of methodological inquiry, I set out to first understand the different pieces of data collected, then to identify the emerging patterns of data, and finally to start making sense of the relationships between these patterns to identify and construct the major themes found within the data.

This process is one that began upon the first initial contact with the data, in other words, in the actual interview setting. As a member of the larger research team, I was one of multiple researchers involved in the interview process. I had specific involvement with two interviews, both conducted close to the onset of the research project. Both were the second interviews conducted and so the study participants were already somewhat comfortable with the interview process. In preparation for these interviews, I listened to the electronic transcripts while following along with the transcripts. I also made pre-interview field notes to help organize my thoughts and to set out concrete goals for the interview. Lastly, I spoke with the interviewers who conducted the initial interviews in order to understand their interpretations of previous meetings with the teen and to ensure that all additional questions to be asked of the participants were duly noted.

Taking part in the actual interview process allowed me to have face-to-face contact with the participants and as such, put a face to a name. I was able to pick up on certain extraneous physical characteristics of both the individual I was interviewing, such as whether or not scars were visible, and the environment they chose for the interview. For example, on one visit, I noted there were several religious icons around the home, thus enabling me to have a clearer idea about the role of religion in that family's daily life. Interacting directly with the adolescents in the context of their family and home settings also gave me a chance to experience them as "normal" teens despite all that they had been through related to their CHD. Meeting these teens and connecting with them on a more personal level gave me the opportunity to reflect on more than just their words.

Listening to the digital recordings of the interviews also afforded me the opportunity to more fully understand the contexts and meanings of the interviews because of subtleties and intimations that are not as readily conveyed when reading the written transcription. For example, in transcribing the second interview with one young teen, the transcriptionist did not indicate each time this individual laughed. Listening to the recording, I realized that the giggling occurred frequently and this made me wonder if the teen was nervous. Humour and other emotions can be difficult to interpret without the addition of tone and non-verbal body language to guide you, and so listening to the interviews as well as reading them was important in this process of living in the data and gave me the added appreciation of what I gained from personally conducting two of the interviews.

An additional means of living in the data was the conversations that I had with the two interviewers who conducted a majority of the interviews. This was another way of gathering new insights into the interviews and therefore the teens themselves. As I read through and listened to the interviews, I began to sort out and connect the many pieces of the puzzle and as Thorne (2008) puts it, I was able to differentiate between what constituted relevant information, as it pertained to the phenomenon studied, and what was "only peripherally relevant" (p. 123). This in turn helped focus the insights I gained from this first stage of my analysis into categories of data which subsequently became my coding structure.

Coding Structure.

I began to create a coding structure after I had listened to a majority of the interviews (See Appendix E). Specific characteristics of life as a teen with CHD began to emerge and as I became more immersed in the data I was able to move from having specific data points to seeing the relationships between and among them. This in turn enabled me to develop a coding structure that was both relevant and effective. Once the coding structure was in place, I began to go through the interviews for the third time and analyzed the data as per the coding structure. Upon completion of the first four or five interviews, I reworked my coding structure to remove some codes that overlapped with or duplicated other code categories and that became less relevant as my coding progressed. For example, I had two different categories to capture issues related to strategies for coping with CHD and collapsed them into one code category. Additionally, as I gained further insight into my data, I became aware of the need for a category related to trust between the teens and the health care setting. It was only as I became immersed in the data that I was able to see the need for such a category. I was thus able to code the interviews, and enter the codes into the N-Vivo 7 software program, and subsequently have access to a manageable data set of coded interviews and nodes of coded data for further consideration. Within the coding structure that grew from my understanding of the data, ten categories with several subsequent secondary categories were developed and it was from this overall picture that I was able to identify the three main themes that constituted my findings.

Quality of the Research

Interpretive description is a means by which nursing specific knowledge can be developed and disseminated (Thorne et al., 1997). To enhance the credibility of my findings I made sure that I was transparent about my decision making process as I developed my coding structure making sure that the "specific decisions [were] presented and contextualized within the larger picture" (Thorne et al., 2004, p. 15). I also was careful about how much attention I paid to specific quotations, especially those that were dramatic in nature, but not necessarily relevant to the findings. Focusing on specific quotes over the bigger picture can lead to errors in the analysis (Thorne et al., 2004) and less credible findings.

Qualitative interviews yield data that is subjective in nature however this in no way makes the data less meaningful; instead it is important to ensure that the interpretations made about the data are in fact credible (Thorne, 2008). Concerning rigour, Sandelowski (1993) discusses the idea of qualitative research as a form of art in an effort to explain the importance of remaining true to the qualitative work while ensuring its validity. Using the example of renowned artists Dali and Picasso, Sandelowski points out that "just as Dali's art is no less valid than Picasso's by virtue of differently re-presenting common phenomena, so too may different qualitative representations of common phenomena all be valid ones" (p. 3). From this, it becomes evident that gathering data from a variety of teens in a variety of methods is valid and will yield trustworthy data. Remaining true to the stories gathered in this study was one way of ensuring validity and that meaning was not changed or adjusted to tie in with ideas emerging from other participants' data. Every effort was made to include the participant's exact wording so as to portray the intended meaning.

One key method for ensuring validity according to Thorne (2008) is to engage in the process of what she calls member validation, or member check, which is where data is gone over again with participants to establish whether or not the researcher's interpretations of collected data are meaningful. In this study, clarification and elaboration of findings was sought throughout the interview period and in the subsequent interviews with the same teen, in an attempt to continuously ensure that the teen's ideas and beliefs were not misconstrued.

A key aspect with rigour and credibility is to ensure that interpretations remain true to and grounded in the data. Field notes that detailed the context of the interviews, which is often difficult to ascertain from interview recordings, also helped me gather contextual details both before and after each interview. As I listened to the interviews, I jotted down any thoughts or ideas that came to me. This was done prior to building my coding structure and was extremely useful at the beginning stages of this process to help streamline my thoughts and to see on paper that recurring themes were becoming evident. Another method of ensuring credibility and validity of my results involved building a table that outlined my findings visually. This process whereby I ensured that all participants' voices were heard was painstaking but it enabled me to view the data at a glance and thus my interpretations of the interviews were more thorough.

Ethical Considerations

The project coordinator for the larger study made the initial contact with potential research participants over the phone. From this point, a brief description of the proposed study was provided. When both the parent and the adolescent agreed to participate in the study further back and forth communication between the coordinator and parent culminated in a confirmed date and time for the interview. Consent was obtained from both adolescents and parents prior to the start of the first interview. Information letters and consent forms were reviewed and parental consent and adolescent assent was obtained at the beginning of the interview (see Appendices F, G). The necessity for parents to agree to have their child participate in the study is noteworthy. The teen was then given the opportunity to provide assent and the interviewer, in the privacy of the interview setting, gave the teen the opportunity to decline study participation even though the parent had given consent. None of the teens declined participation. Both parents and adolescents were informed of their right to withdraw from the study at any time. Additionally, they were informed of risks and benefits that may result from their involvement in the study. At the beginning of the second and third interview previously signed assent sheets were reviewed with the adolescent so as to maintain the concept of ongoing consent, thereby allowing the adolescent to remain aware of this ongoing process.

Maintaining participant confidentiality throughout the analysis portion of this study was crucial. Each teen was given a pseudonym to protect their identity and all identifying factors (e.g., hometowns, physicians, and surgeons) were removed from the transcript. In an effort to further protect the teens' identities their pseudonyms were not used in this paper. Although the retelling of each teens' story would have added to the richness of the data, use of their pseudonyms could have led to a breach of confidentiality should the teens have recognized themselves, and thus they were removed. Additionally, the pronouns he and she have been used interchangeably to further protect the teens' identities.

Adolescents can be considered a vulnerable population due to the fact that they cannot give informed consent for themselves and they may also be considered as particularly at risk for being subjected to manipulation and intimidation (Kopelman, 2003, as cited in Kopelman, 2004). Special care and attention was therefore given to this unique group of participants. It was critical to gain the trust of these individuals and the first few questions asked were essential in helping achieve this goal as they focused on helping put the adolescent at ease and on helping them to feel comfortable answering further questions.

Conclusion

Interpretive description proved to be an appropriate method to investigate teens' perceptions of their day to day life and the quality of their life in view of their CHD. Themes and patterns were identified and analyzed as they were recognized and thus a "rich interpretation that allows *a priori* theory to be changed by the logic of the data" (Thorne et al., 2004, p. 11) was possible. My initial thoughts about what constituted my findings changed over time as I lived in the data. What I found over time was that the more I read and listened, the more interesting and relevant data I unearthed. These teens proved themselves to be articulate, dynamic individuals who had wonderful information to share and who were generally quite happy and genuinely eager to share their stories with us, the researchers. Focusing the research methods to reflect interpretive description helped me gain a better understanding of how adolescents with congenital heart disease describe their day-to-day life and relate to questions about the quality of their life. What follows in the findings section is by no means exhaustive but is meant to be an interpretive description of what I found to be most striking in the data especially in terms of guiding future clinical practice.

CHAPTER FOUR

Findings

In total, parents and teens from 14 families were enrolled in the larger study. Of those 14 teens, two were developmentally and cognitively delayed and thus I did not include them in my analysis and two teens were heart transplant recipients for cardiac conditions that did not meet the criteria of having been born with CHD. My study sample therefore consisted of ten adolescents, six females and four males, ranging in age (at the time of the first interview) from 13-17 years of age. Of these teens six lived in the city and four lived in a rural community (in either a small town or on an acreage). Six teens lived in households with both of their parents; four teens lived in single parent households and all but one teen had regular contact with their other parent. All teens but one had at least one sibling; three were the oldest child, five were the youngest child and one was a middle child. The teens' diagnoses were as unique as each teen and yet they all but one shared the commonality of having been diagnosed with CHD during infancy (from two days old to five years old) and all had previously had at least two heart surgeries to treat their cardiac malformation. The teen who was diagnosed at five years of age was included in the study because although she was older when diagnosed, she did meet the inclusion criteria of having been born with a congenital heart defect that had been repaired surgically. For four teens, the most recent surgeries occurred between two and half years of age and six years of age and for six teens their most recent surgeries occurred within the last two to three years (age range: 12-16 years). Of the six teens taking medication at present, three teens took two or fewer medications per day and three took three to four or more per day. Of the four teens who took no medication on daily basis, two teens were required to take antibiotics prior to dentist appointments. Despite the diversity in the teens' cardiac diagnoses, timing of treatment, and family configuration, commonalities and shared experiences were evident and emerged early in my analysis.

One of the most striking shared characteristics of the ten teens in this study was their overriding view of themselves as similar to their peers and friends. This was in contrast to their history of serious congenital heart disease and their need for ongoing care and monitoring from cardiac specialists. Another commonality among the teens in this study was their willingness and ability to candidly share a snapshot of what it was like to live the life of a teenager who in their minds just happened to have grown up with a congenital heart disease. The teens openly and articulately spoke of their life at school, at home, at work, at play and as cardiology patients. Overall, I found that these teens related to the concept referred to as quality of life (QOL) but they did so in a less straight forward manner and as such required more from the interviewer than simply asking the question "How would you rate your QOL?" As is often the case with qualitative research, hearing the stories the teens had to tell offered up a richer understanding of how growing up with CHD had affected teens both in terms of day-to-day life and QOL issues.

Quality of Life

Understanding QOL conceptually did not come easily to this group of teens, as would be expected, based on their development and ability to comprehend the abstract nature of this concept. The teens struggled somewhat with the actual term "quality of life" and for the most part fell back on providing a definition that was broad and did not relate to their lives. They described it as being how good or bad your life is and how happy you are. Two teens made direct reference to a definition of QOL that they were taught in Grade 9 social studies. One such definition was “It’s like, it’s like how you enjoy life.” The other teen referred back to a country’s quality of life and compared that to an individual’s quality of life saying that it’s:

> 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, are they mediocre compared to other countries? Like you don’t always have to be the smartest or the best at everything. It’s more like are you average? Are you happy?

With regard to completing the QOL survey, four teens described it as being easy, almost as if they thought of it as some sort of test that they would either pass or fail. On the one hand there seemed to be an understanding of the terms used in the survey and certainly they answered all the questions without need for extra guidance. But when questioned on the overall meaning or concept of QOL, the teens struggled resorting to that same Grade 9 definition. This question was asked immediately after they had completed the questionnaire and so one might have expected them to relate QOL to their own life, but this did not occur. Two teens responded to questions about the questionnaire in concrete terms saying “I liked this question, I didn’t like that one”, but not in an overall “my QOL is good or bad” although one teen did note that he felt the questionnaire was reflective of himself – a teen with CHD.

Regarding the question of how teens with CHD relate to questions about QOL, it became evident that this was done in an indirect manner. For example in conversations about not being able to keep up with peers, needing to take medications, not participating in sports, the teens were in fact talking about how the quality of their life had been affected by their CHD and related sequelae. A key finding of this study is that the teens chose whether or not they wanted to use CHD as a reason for being included in whatever activity was occurring and in turn made CHD a background or a foreground issue. Throughout the interviews, each teen spoke extensively about the various factors that contributed to QOL such as their development, their physical characteristics, their involvement at school, their employment situations, their futures, and especially their interactions with family, friends, peers, their health care practitioners and the community. What follows is a description of how these components factored into the everyday lives of the teens and implicit within this description is the knowledge that although QOL was not referred to explicitly by the teens, an awareness of its existence (as a concept) was present.

Development

On the whole, the teens who participated in this study described themselves as being normal or similar to their peers. In terms of development from the point of view of Erik Erikson, these 13-17 year olds should have been at Erikson's fifth stage of development and indeed this was the case. According to Erikson, this stage of development is known as the Ego Development Outcome whereby teens struggle with acquiring a personal identity while overcoming role confusion (Potter & Perry, 2001). These teens, like their peers, were working at coming to an understanding of both their role 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 towards independence and there was evidence of this process in the data.

The 13-17 year old teens were at different points along their way to becoming adults and yet they all spoke eagerly about the various ways in which they were testing limits, seeking to become more independent, and developing a sense of self. These teens were making their way to and from school on their own, they had jobs and they were beginning to think about their plans for the future. The research finding of teens with CHD related to their “less ordinary life” (McMurray et al., 2001) was presented to the teens in our study. In response to this line of questioning, many of them actually described the opposite. One teen in fact responded with “No, I think my life is pretty ordinary” and another told us that she did not think she was much different from her friends or peers. Another teen spoke of having nothing in common with his peers from a local heart support network: “everyone else that goes there [the local heart support network] is like really, really active but I like art and I listen to my iPod and I like to walk around with my friends, discussing things and they’re like ‘Let’s play soccer.’ ” In this situation, it appeared that although this teen shared a commonality regarding CHD with the teens from the heart network, in truth, he would rather have spent time with friends, people he identified with for reasons not just heart related. Or in other words, the pre-existing heart condition similarity was not something this young teen identified with as a rationale for being different. He identified his interests in art and music as bigger, more valid reason to be seen as different. This sentiment was echoed among several other teens in our study. One participant touched on the idea of teens developing a sense of self when she went on to say “So you realize how much you don’t really have in common and then you kind of have to change for them, just in that like three hour span, but you only see them like three hours, three times a year and it’s just, it’s okay.” This well-articulated insight exemplifies the growing, learning teenage mind; this teen in particular seemed to have grasped the idea we as adults understand well: some social situations call for a change in behaviour, if only briefly, to conform to the group norm. This teen understood this, was willing to accept this and therefore demonstrated genuine wisdom and personal growth. In contrast to this evidence of growing maturity, another teen also related that his mom woke him up in the morning for school, turned off his fan and put his daily medication on the kitchen table at breakfast and in so doing illustrated the gap that exists between dependent teens and independent young adults.

Six of the ten teens interviewed saw themselves more similar than dissimilar to their peers. Of those who saw themselves as different, three out of four of them felt that not being able to participate in gym class was a primary factor in what set them apart from peers. The need to miss school for doctor’s appointments, tests or surgeries was noted as a primary factor for one teen and as secondary factor for two of the four aforementioned teens that set them apart from their peers. Interestingly, the rest of the teens in our study spoke of a need to miss school, undergo medical tests, and other activities due to their CHD but did not describe these as factors that stood out as causing them to see themselves as different, or as less than ordinary and indeed one teen spoke of “just [acting] like a normal 16 year old kid.”

Physical Characteristics.

In terms of physical characteristics, analysis of the interview data pointed to the reality that the teens in this study were different from their peers. The two areas of difference revolved around actual involvement in physical activities on the one hand, and body image on the other. Seven out of ten teens interviewed stated they had no concrete physical restrictions placed on them and that they took part in a variety of after school activities such as soccer, volleyball, basketball, and dirt biking. Among the teens with no concrete restrictions, there was however an acknowledgement of certain limitations that they attributed to their heart condition. These limitations seemed however to be self-imposed or self-directed and took into account the teens' knowledge of their condition, common sense and a feeling for when they were pushing themselves too hard. One teen talked about her parents being concerned for her when it came to participation in gym class stating that "Like half the time they 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 stuff, like if it's too much or something." 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 to take a break if needed.

In terms of the three teens who reported having physical restrictions, the reasons for the latter were varied. One teen spoke of needing to be very careful vis-à-vis physical activity due to the fact that he was taking Coumadin "[because] I can't get hit in the head," and because he experienced intermittent chest pains. He then went on to admit that missing out on gym class was not such a bad thing. Yet another teen, who did not have physical restrictions, also took Coumadin although she acknowledged that she should be a bit more careful than her peers but “I’m not really; if I fall it might be a bigger bruise,” this in contrast to the above mentioned teen’s approach. In terms of these different approaches, I question whether or not the first teen (the one afraid of hitting his head) would choose to participate in any physical activities if he had the option. It seems that part of his lack of participation came from a lack of interest and so it would be difficult to decipher if the latter was what was preventing participation, or if in fact it came from a fear of being injured or of changing his heart health status. Yet another teen spoke of not wanting to participate in gym class but attributed this to her “laziness” and one young man spoke of his participation in sports when he was younger but reported that he was lazy now and so chose not to be as physically active.

In terms of body image issues, all of the participants but one spoke about their scars but the content of the discussions varied from teen to teen. Of the four males interviewed, one did not mention anything about his scars, one spoke of being nervous about showing his body and the remaining two spoke of being unbothered by them, with one stating “If they’re all like oh [teen’s name], 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.” Among the females in our study, there seemed to be an increased consciousness of their scars and the need to potentially cover them up depending on where they were going. There was some discussion around the type of shirt one could choose to wear, be it a high-neck or v-neck shirt as well as some discussion around who the girls felt comfortable showing their scars. Two girls commented on the awkwardness of going swimming and deciding what type of cover-up would be 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 and I just continue on," and in so doing, revealed the comfort level she had with her own body image despite her scars. Two other girls spoke of the embarrassment of having their scars seen by their peers at school but that they were unbothered by strangers seeing their scars and so dressed differently according to the social situation they found themselves in. Overall, it seemed that although the teens were aware of their scars, they felt comfortable enough around both family members and friends to reveal their scars without cause for concern. One teen in particular felt at ease enough with her scar to come to the interview with a low necked t-shirt, thus revealing her comfort level with her scar. These teens have had their scars since birth, with some new ones added along the way, and so know themselves in no other way and thus seem to recognize that friends and family who know them well will also take this in stride. One teen echoed this thought about a lack of concern with family and family friends when he observed that "we have this like 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."

As comfortable as the teens were with their scars among their friends and family members, their hesitation in revealing all with school mates was evident; herein the teens seemed more concerned with how this group would react to them than any other group. Peer groups such as those found at school can be particularly hard on each other and this certainly was the case here, where many teens felt the need to cover their scars so as not to make themselves a target for bullies. The youngest teen in the study, for example, only wore t-shirts with high necks when she was at school, because as she put it: "I'm just scared that they'll [classmates] be like oh, like make fun of me or something." However, once out in public, she felt no need to cover up because at school she knew the people and this may have made her feel like more of a target for any potential bullying. This appeared to have been a bigger issue for the participants when they were younger as presently many of them, like the one mentioned earlier who was happy to show his scars to anyone who asked, were less concerned than they once were about how others viewed them. This was especially noticeable when the teens mentioned that they were mostly indifferent to the looks given to them by strangers on the bus, at the mall or at the pool. This ability to accept themselves, for who they were, scars and all, revealed insight into their sense of self as individuals who were unique for reasons other than just physical.

School/Employment.

When it came to school matters, a range of school performance could be seen among the participants. The majority of teens in this study (seven out of ten) indicated their marks were average and rated themselves as average students. Among these seven teens, one teen had been diagnosed with dyslexia and another teen noted that she had needed extra help from teachers until she was in grade 8. In her words: “It was just kind of like the teachers had to give me a little bit more help than anyone, than everyone else, like um, a little bit more time on major assignments or just things like that.” One teen did not mention trouble with school, except to say that she was home schooled. The remaining two teens spoke of struggling with school; the youngest teen in the study described having trouble with math, trouble with tests and talked about a need to be in a separate room when writing tests so as to remain focused. The other teen was in a special education program and spoke of being at a third grade level in math. With the exception of these last two teens, the study participants acknowledged that at times school had been somewhat of a challenge due to missed classes for appointments, but they did not use this as an explanation for their grades. One spoke of having grades that fell below average but attributed that to laziness; the interviewer asked if she felt she had to work harder than other kids and she responded by saying that “Um, I’m kind of lazy and don’t. So, yeah. I don’t really work that much.” For these teens then, growing up with a CHD did not seem to be an issue with regards to how they performed at school.

In addition to their schooling and school-related activities, many of these teens were involved in after school jobs, ranging from work on the acreage, to babysitting, to being a waiter at a restaurant. Two young men mentioned jobs they would like to hold in the future (joining the police force or the army) but that they would be unable to do so due to their physical health. No other teen mentioned a restriction with regards to job possibilities either at present or in the future. Again, these teens viewed themselves as typical teens doing typical jobs, for monetary purposes or to just be able to help out with household chores. This involvement in the workforce was another example of teens seeking to identify themselves as individuals separate from their parents/families and friends/peer groups.

The Future.

The comments these teens made regarding their future were varied; some focused on future careers, some focused on moving out of their family home and others focused on how their needs would change with respect to the medical help they currently received from their parents. With respect to future careers, teens spoke of going to university, working as businessmen, doctors and massage therapists, of becoming auto mechanics and of working in sales. Other teens focused more on how things would change for them when they moved out of their parents’ homes and how the relationship with their parents would inevitably change. One of the older teens in the study spoke of possibly buying a house in the future, something she thought her parents could do for her but that she would like to do on her own; for this teen it was most important to know that “I can go to them for help or that they’ll always be there for me.” When speaking of her parents’ over-protectiveness, one of the younger teens talked about how “if” she had a place of her own, her mom would probably be there all the time, checking up on her. Again, analysis of the data that the teens provided regarding their thoughts about their future hopes and dreams, and thoughts and concerns about what was yet to come in their lives revealed that they were not that different than ‘typically’ developing teens. Few talked about their future in terms of their heart problems or related concerns about how their heart condition would influence their future plans even though they were clear that the reason they were participating in the study was because of their CHD. Additionally, none of the teens spoke of being given assistance to prepare them for their eventual transition to adult care.

Thus far I have developed the idea that the participants in this study were in many ways, normal teenagers, dealing with normal issues and working towards becoming independent young adults as evidenced by their involvement in school work, after school jobs and an increased sense of responsibility related to familial duties. At the same time, I have shown that there are some characteristics that showed these teens as different, for example their physical limitations, scars and body image issues. On the surface, these teens came across as perceptive individuals who had learned to take their early-in-life CHD diagnosis in stride and who on the whole saw themselves as normal teens with normal adolescent concerns and anxieties. What we do know though, is that there is one factor which unavoidably marks these teens as different from their peers and that is their

CHD. And so as each teen described the different ways in which they saw fit to portray a life of normalcy, I would come across yet another unique identifier that denoted them as different. I will now highlight what it is about these teens that made them different from their peers.

CHD: Background and Foreground Considerations

Although the teens in this study gravitated to a presentation of self as normal, even ordinary, they seemed to almost be capable of situating the diagnosis of CHD into the foreground when it suited their needs, and then just as easily return it to the background. CHD became a card that could be played when it suited their needs. For example, the teens spoke of their involvement in gym class where CHD became a foreground issue, and when the teens talked about being ‘normal’ teenagers, with normal everyday concerns, CHD became a background issue. As I listened to the interviews, I came across several instances where seemingly offhand comments were made by the teens that appeared to point out a very clear distinction between themselves and their peers. Although they were often aware of these distinctions, they did not consistently make them an issue. Upon reflection, to best understand the foreground/background theme, I needed to consider the teen firstly as an individual, to comprehend how he or she personally sorted out the complexities of living with CHD. The next context to examine was home, the school environment and the community. The last context I considered was the health care setting. 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 helped me to understand the nuanced relationships within the data.

The individual level.

Focusing firstly on the teen as an individual I will portray how the teens regarded their CHD diagnosis as a background issue by relating to their everyday life and their views of themselves as normal. The matter of having CHD did not seem to be something that many of teens in this study considered as being a defining aspect of their persona. In fact one young teen went so far as to say “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 (e.g., fitting in, having friends, being able to do what her peers do) were what concerned her. For this teen, who did not take any medications (except for antibiotics when she went to the dentist) and had no current physical restrictions, her CHD was somewhat of a background issue. In many instances in her day-to-day life, the CHD card did not need to be played. She was able to go about her daily routine with little cause for stopping and considering the impact growing up with CHD had had on her. This sentiment was echoed by many other participants at various points throughout the interviews.

The one exception to this was our oldest teen, who unfortunately at the time of the interview, was experiencing new health complications due to earlier heart problems. Of all the teens in the study, this one was the most likely to tire quickly from whatever activity he was doing, be it sports related or work related and he was also taking the most medications. And yet when asked about how he would describe himself, he did not use his CHD diagnosis and subsequent complications as descriptors of himself. Instead, when asked to describe himself, he said his heart problems “didn’t even go through my mind when I was thinking about that.” And so although the context of the conversation was different when compared with the comments from the last teen (who talked about life just being regular), both teens were able to place their CHD diagnosis squarely away in the background. It was evident in these teens' accounts that this seemingly reflexive and instinctive action whereby their heart related health problems were situated away from the centre enabled them (the teens) to feel 'normal' and therefore part of the group.

For the most part the health care needs of these teens as they pertained to the CHD, at this point in time were, from their point of view, relatively minor. Doctors' appointments ranged from every six months to every two years, many teens were on no medication, or took a baby aspirin (81 mg) pill once a day and as discussed previously, the physical restrictions were for the most part, minor in scope. They spoke candidly and openly of their physical health needs, making it sound as if these mundane details were merely that, details. Four teens made specific comments about the eventuality of needing their artificial heart valves replaced once they finished growing and did so in a manner that was matter of fact and not worth dwelling on. When one young girl was questioned about the nature of her doctor's appointments, she nonchalantly replied that "I sit down and do some waiting and then I go in and he just kind of listens to my heart and usually just says that everything's okay and then I walk out." At times, it almost seemed as though the teens did not need to show cause for concern as their health care needs were minimal, they were on few if any medications and so everyday life was 'normal' for them.

In keeping with this train of thought, it became evident how much CHD had become normalized for one particular teen. When the topic of her last surgery was brought up, she was questioned about the amount of attention she paid to her heart defect in her life today. At 15 years of age, a surgery that occurred over six years ago seemed to be of little concern to this teen, a thought confirmed in her statement

> Well I never really paid attention to it in the first place cause I've, ever since I remembered 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; the extent to which CHD was a part of them. This diagnosis and its sequelae seemed to be 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 care practitioner) to also place the heart problem in the background and out of the way, allowing for the continuation of the 'normal' life.

Keeping all of this in mind I now show how the teens conversely 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 their involvement in gym class. One young girl for example, who described herself as 'normal,' clearly typified this when she talked about not wanting to partake in gym class, due not to physical restrictions, but to her laziness. This is something she felt she could get away with, with substitute teachers by saying things like "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 [gym class activities]." On the one hand then, she portrayed herself as being similar to her peers on many different levels, and yet she brought her CHD diagnosis to the foreground to get herself out of an activity she did not enjoy. In so doing, she was able to play the CHD card and use it to her advantage, in direct contrast to how she kept that card in her hands in the other situations where she spoke of CHD being a part of her life to which she did not pay attention.

Throughout her interview, another teen articulately expressed how different his CHD has made him from his peers and often painted this in a less than positive light. And yet when asked about the best part of having CHD, this teen talked about the extra attention received from friends and family and how this was a good thing. And so although on the one hand he did not always like being different from his peers, he placed this distinction into the foreground when it best suited his personal needs. When the same question was asked of another teen, the answer given focused on the extra activities he was able to participate in as a member of a local heart support network: “Like we go tubing in the wintertime. I get to go paintballing next Saturday. I get to go to more picnics.” Again, the fact that he had CHD was what enabled him to participate in these activities, and so the CHD card was played and situated in the foreground and he considered his heart problems to be a good thing.

These examples show the teens in such a way as to understand that as individuals, they struggled within themselves to understand the place CHD played in their everyday lives. Their heart problems and sequelae were an intrinsic part of their unique makeup and as such could not easily be separated from them, regardless of the situation. And yet, they still seemed capable of situating this diagnosis from the foreground to the background in a reflexive way that even they perhaps were not really aware of and so the CHD card was played in some situations, and withheld in others.

At home, at school and in the community.

When the teens talked about their life at home with their family and at school with their friends, they depicted their heart problems in such a way as to convey considerable variation on their CHD being a foreground or a background issue for them. The manner in which this occurred seemed consistent with the developmental stage they were at whereby they were striving to separate themselves from their peers and families, while still hanging onto a need for protection provided by being a member of a large group. This most commonly occurred 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 to disclose about their CHD and the manner in which they would convey these details, depended on whom they were with and how they were interacting with them.

In terms of this being a background issue, the teens often chose to keep the details private when interacting with people they either did not know or with people they did not necessarily see eye to eye with. For example, one participant spoke with irritation about her stepparent’s knowledge of her heart condition and about how much it bothered her that this person felt they could talk about their stepdaughter’s condition when “it wasn’t even like my parent. It was like my step [parent] so I was like grrrr.” She felt the issue of her having CHD should not have been her stepparent’s concern and as such wished for her CHD to remain a background issue and chose not to play the CHD card in that moment.

One other teen also talked about her diagnosis and subsequent heart problems as being a personal thing and that she would disclose details of ongoing problems to close friends but did not feel like she should have to tell everyone everything. For instance, she would tell those who asked about her surgery when she was nine but did not tell them about the surgery she had when she was two “unless it really, really matters. They get all askie about it.” This teen spoke of this making her uncomfortable and mad and so by giving out selective tidbits of information, she was able to control how much people knew about her condition and so could keep as much of it in the background as she desired.

In the community setting, several examples of teens wishing for their heart problems to remain private were brought up. Notably, an older teen spoke about the weird looks he would receive from people when he wore a basketball jersey (because the scar was visible) and how it made him push himself harder to prove his ability to play basketball was unhampered by his CHD. In so doing, the heart problems took a back seat to his physical abilities as a basketball player and as such enabled him to situate that diagnosis into the background of his life and thereby demonstrated his resolve to not let CHD direct his life.

As much as these teens conversed about their need for privacy concerning their CHD, they also provided many examples of the opposite of this occurring. When one of the older teens discussed the best thing about growing up with a heart disease, he focused on how much extra attention he used to receive when he was in elementary school. He spoke of how important it was for his parents that he be treated as a normal child and that his heart defect was not a cause for being singled out. Perhaps this is why he really relished the extra attention he did receive from teachers and friends and why it was that, in his words, he thrived on that attention. So while this teen in particular over and again talked about acting “just like a normal 16 year old kid,” his CHD had a prominent place in his life and his overall open and enthusiastic manner likely were linked to his CHD diagnosis and as such had an effect on his day-to-day life. In this way, a need for privacy became a card that could be played, dependent on the situation at hand and as such allowed the teens to situate CHD in the foreground or in the background.

At home, playing the CHD card and thus making it a foreground issue, was done readily. One study participant talked about how helpful it was to be able to sit down and initiate a discussion with her parents about her condition and to ask questions about her blue lips and about “why was my body born blue.” She explained that because her parents had taken the time to answer these questions and others, she was better prepared to answer the questions her peers asked of her and this was something she enjoyed doing: “I can explain it to people which is really fun. I explain it the easiest way possible but if they wanted me to go really in depth, I could.” For this teen, understanding her medical condition made the process of disclosing the details of her CHD an uncomplicated affair. The open and honest approach her parents used made it easy for her to bring her concerns about her heart problems into the foreground without fear.

When it came to disclosing details of their heart conditions to peers and teachers at school, the teens had different approaches. While some of the teens felt their CHD was a private affair, others were happy to disclose these details. One teen talked about growing up in a small town and knowing everyone in his school. He was unconcerned with disclosing the details of his heart condition with his peers. When people saw his scar, they would often ask him questions about it which he felt at ease answering, likewise, he reported doing the same when he got to know someone new in his social circle. His CHD was brought forward as a foreground issue both by him and by others but again he, like other teens in the study, felt at ease telling others about it.

Another teen reported feeling comfortable disclosing the details of her surgery and heart condition with her peers at school. She reported that she wore clothing that did not always conceal her scar and so when people would see it and ask about it, she felt comfortable telling them about the hole in her heart that needed fixing when she was two years old.

When it came to discussing their heart problems with strangers from the community, be it on the bus, at the pool or mall, the teens again had different feelings about how best to deal with the stares and questions. When surrounded by strangers, one girl in particular felt comfortable revealing her scar at the pool because “I’m never probably going to see any of the people again.” In a bathing suit, her scar marked her as different from others and yet this was of no concern to her as long as no one she knew saw her. When wearing a bathing suit, she brought her CHD into the foreground in an overt way and she maintained in that instance to be unbothered by the stares and/or questions. Again, the CHD card was played in such a way as to ensure the teen was still in control of the situation.

Overall, the majority of the teens interviewed gave the impression of being open to telling others about the details of their CHD as long as they were in control of the situation. In this way, they were able to dictate what was disclosed and to whom it was disclosed. When this occurred, the teens’ overwhelming response was one of satisfaction at being able to answer questions about their often complicated medical histories. When they were not the ones guiding the conversation about their heart problems, like the example of the teen with her stepparent, then the teens were more likely to want to make the heart disease a background issue. Two teens in the study were notable exceptions; they both spoke of being uncomfortable with questions from peers and strangers. Based on their responses to questions about disclosure however, it appeared that they disliked the questions due more to the difficulties they had in actually describing their condition, than to a discomfort with disclosing the details.

The examples given throughout this section have helped identify the different situations where the teens played their CHD card, whether it was at home, at school or in the community. Depending on each individual's personalities, CHD was seen as a foreground and background issue and although at times the decision to play the CHD card is reflexive or automatic, there were definitely examples whereby deliberate playing of the card occurred.

The health care setting.

In this final section, I detail how the teens in this study interacted with the health care professionals they had been involved with over the years and how they related to the actual health care setting (e.g., hospitals, doctors offices). The data generated in our interviews with teens relating to the health care setting were most interesting for me perhaps because this data best brought to light the lived reality of the health problems these teens had grown up with and how they have worked to assimilate them (the health problems) into everyday life. From an outsider's perspective, missing school on a regular basis, taking medication before routine dental appointments and overnight stays in hospitals are in no way part of a 'normal' child's upbringing. And yet for these teens, an attempt to normalize these activities seemed necessary in order to make sense of it all. The issue of their heart disease being in the background or in the foreground is thus somewhat different in this section when interpreted in light of the health care setting.

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 endeavoured to present 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 in many ways this routine was a background issue for them. It only became a foreground issue when for example a new test was being done, or when the routine was interrupted, like when a teen had an appointment with the doctor and they were with the parent who does not usually come to appointments.

Of those interviewed, eight of the ten teens conveyed a certain sense of comfort surrounding their association to both hospitals and the health care providers they had encountered. The terms “used to it [the hospital],” “used to them” [the health care practitioners – doctors, nurses, lab techs]” and “comfortable with” came up repeatedly in the interviews when the discussion turned to the hospital setting. One teen reported that “I’m a lot more used to doctors and everything. Needles don’t bother me or anything.” He followed that up by saying that he does not spend a lot of time in hospitals anymore. Another articulate teenager’s description of her encounters with the health care setting was particularly noteworthy. This discussion came up when she was asked what the best thing about having CHD. She responded by saying that the best thing 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. She reported that:

> It’s just when I go there, I don’t feel, 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.

This teen saw her CHD as a background issue when she was in the hospital, and going to the hospital, a place she described as “homey”, was not anything out of the ordinary. Perhaps what could have been added to her last statement is that “it is not out of the ordinary, *for a teen like me*”, because again, from the outside looking in, and from the perspective of a parent of a healthy child, kids having to spend time in hospitals is not a ‘normal’ childhood activity. For this particular teen however, there was nothing out of the ordinary about her routine hospital visits and doctors appointments. Another of our teens, who was only 13 years old at the time of the interview, also spoke casually about his need for routine blood work twice a month. He seemed to think it was no big deal that he needed “CBC and INR counts” done often and spoke casually about deciding when he needed to go: “Well I kind of just go whenever I want to cause well sometimes it’s like twice a month and that’s what I usually do now.” This teen also reported that he often went to medical doctors appointments on his own if he had a cold or minor illness and that it really was not that big of a deal because he was used to it.

There were two exceptions to this in our study, as two teens found that visits to the doctor were somewhat unsettling and cause for concern, but for different reasons. The elder teen's discomfort was with the health care practitioners themselves because he felt it was difficult not only for him to communicate with them but to understand what they were telling him. This particular teen was the only one in our study who could be classified as being in the process of transitioning to adult care. In the care of both pediatric and adult specialists, he was straddling the two worlds and he spoke of the difficulties he was having with this. 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 was not easy. He spoke from experience when he described his encounters with the adult group:

> 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.

This teen had difficulty communicating with the doctors and nurses he encountered and so it is in no way surprising that he would find it uncomfortable or disconcerting to go to his doctors' appointments. For her part, the other teen who was uncomfortable with hospital visits spoke of being afraid to go to the doctor, because "well sometimes I'm afraid that everything won't be okay, but it usually is, so..." She also told us that in fact her doctor kind of scared her and that "his hair is kind of weird" but then admitted once the appointment was over, she found it was not as bad as she had thought it would be, especially when everything turned out to be okay.

As a foreground issue, the CHD card was played when the boundaries of what the teens deemed to be normal were breeched, so for example when a new test was necessary or when they had to see the doctor on their own for the first time. The teens' comfort zone and what they were previously used to was no longer the same and so immediately, having CHD became a foreground issue. One of the teens spoke of this when recounting his last doctor's appointment where two tests were done instead of one. This particular teen had previously had one of the tests done quite regularly and so was comfortable with the procedure being done. However at the last appointment prior to the interview, he was told upon awakening from the procedure that an additional and new test (to this teen) had been done as well and this appeared to really bother the teen. On two separate occasions during the second interview, the teen touched on the fact that he had not been told about the biopsy and spoke of how upset he was by this. Having a clear understanding of what was going to occur during each appointment came across as an important feature of the doctor-patient relationship and helped build trust. When this trust was broken like it was in the example given above, the CHD diagnosis and its sequelae were suddenly situated back in the foreground and the teens' boundaries appeared to have been broken.

The experience of one teen with new tests came when she had 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. For her, getting an echo or an ECG done were non-issues and she saw no need for any fuss to be made (by her or by her parents) about them and spent little time talking about the actual process of getting them done. When it came to her MRI and CT scan, she went into a great deal more detail and described the experience as being “weird”. Having missed an entire morning of school, this teen likely would have had to deal with questions from peers when she returned from her tests which would not have been something else to not look forward to. When it came time for the stress test, she and her parent found themselves surrounded by cardiac patients who were adults in the pediatric cardiology clinic area. Her explanation of this occurrence was very illuminating:

> 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 thirty 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?

This description captured this teen’s responses to the change to the normal routine. Her use of the word ‘abnormal’ to describe this made it an even more poignant anecdote as it really highlights the precariousness of the situation, where their ‘normal’ world can so easily be upset by what would appear to be a minor change (in this case, adults as opposed to children in the waiting room). This account revealed yet another strong piece of evidence to support the notion that the CHD diagnosis, though often in the background of these teens’ minds, can easily be situated back in the foreground by seemingly inconsequential details.

In conclusion, as is often the case, the details of our lives that we try to keep private have a way of coming to the surface to greet us when we are at our most vulnerable. In this way, the teens in this study were no different and it would appear that they sought to lead lives that were as normal and ordinary as possible in order to deal with the emotional rollercoaster of adolescence. With changing minds and bodies, these teens were faced with the even greater complication of having to grow up with CHD. As they went about their daily lives, the interactions they had with their families, their peers, their teachers, their health care practitioners and even their community at large helped shape them in distinct ways and forced them, whether they were ready or not, to begin to come to terms with the reality of life with CHD. Like their adolescents in general, they too struggled to figure out who they were and how they saw themselves within the context of their own worlds, a task they appeared to be tackling head on in most instances, as they situated their diagnosis from the foreground to the background of their lives.

CHAPTER FIVE

Discussion

Learning how best to approach the obstacles life presents is a task for all teens to accomplish as they enter young adulthood and begin to forge new paths for themselves. Life for a teenager with CHD is in many ways not different from that of a healthy teenager: developmental milestones are met, school work is completed, and hopes and dreams for the future are formulated. However, certain elements of their lives set them apart from their peers: their physical activity levels and the trust issues they have with health care practitioners and within the health care setting. The three main points of discussion that have arisen and which are further examined relate to normalization, physical activity and decision making by teens for teens. Within this discussion, an understanding of QOL issues and where and how they come into play is addressed. Following this, limitations encountered throughout the study as well as implications for future practice are discussed.

Quality of Life

The question I set out to answer was how do teens with CHD talk about their daily lives and how do they relate to questions about their QOL. At first glance, it would seem that the teens neither talk about nor relate to QOL issues in an overt way. CHD is a part of who they are and who they have always been and therefore is a part of who they will always be. One participant pointed this out when she talked about her family’s ability to adapt to life’s challenges: “Things get… thrown at us and we just whatever, we adapt.” This seems to be what these teens have been doing all their lives; adapting and changing as the need arose.

Getting at QOL life issues is difficult when working with teens by simply asking the question: “How would you rate your QOL?” The matter is further complicated when teens are asked to focus specifically on health-related quality of life because in order to understand HRQOL, the concept of QOL itself must first be understood. The teens in our study struggled with identifying the conceptual meaning of QOL. Discussions about QOL and HRQOL did occur however in a more round-about manner. Conversations that occurred about issues such as not being able to keep up with peers, needing to take medications, and not participating in sports all relate back to the concept of QOL and the teens were in fact talking about how the quality of their life was affected by their CHD and its related sequelae. In their minds, they were more adept at comparing their lives with those of their peers and so were asking the question: Am I normal or am I different? In this way, they were able to situate their CHD diagnosis into their everyday lives, relating it contextually to the interactions they had with families, friends, peers, their communities and their health care practitioners and thus make the choice about whether or not to play the CHD card. Although they may have been unaware of it, they were answering questions about QOL and HRQOL and so in this way, the teens were great self-reporters. Pike et al. (2007) pointed out that “adolescent self-report could provide insight into potential health, psychologic, or social concerns not identified by parents” (p. 13-14) and the knowledge gained through this study will be beneficial in upholding the belief that teens must be involved in any discussion about their QOL.

Am I normal or am I different?

According to the participants in this study, a major factor in what constitutes QOL is fitting in, or not sticking out. Striving to maintain a sense of normalcy throughout their daily lives was important to these teens. In their study on adults living with CHD, Claessens et al. (2005) found that this process of normalization was dynamic and varied throughout their adult lives. Interestingly, these authors reported that those adults who had learned to “successfully [integrate] the limitations and restrictions [of CHD] into their lives… did not perceive the illness as problematic” (p. 6) and that the reverse of this was true for those who were unsuccessful at adapting to the limitations of their disease. The teens interviewed for this study were similar in this respect: they wanted to be normal and in fact did see themselves as normal. They had grown up with CHD and as such it is the only way they knew themselves to be. Going to doctors appointments, missing school and having scars were small parts of their make up; it was what contributed to their uniqueness as individuals. As teenagers, learning to accept and even embrace what made them different was an important step along the way to adulthood and so understanding the effect CHD can have on all aspects of adolescents’ lives is necessary.

The finding that the teens in this study saw themselves as essentially normal was different from that found by Tong et al. (1998). These authors found that in spite of attempts to lead as normal a life as possible, the teens they interviewed found it difficult to see themselves as normal, because of their heart disease. There are several reasons that these findings are different from my own. Notably, the study by Tong et al. was published in the late nineties which was over ten years ago. Surgical techniques have changed and improved over the past ten years leading to a decrease in post-surgical mortalities and morbidities (Leblanc, 2009). The question at hand is whether or not the change in overall health status 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, what other effects is this having on this group of individuals? These teens are not normal; their physical activity levels are different from their peers and they will continue to need specialized care as they grow older. If they are not encouraged to take a leading role in their own health care futures, will their health suffer once they are on their own and no longer under the constant supervision of parents and their pediatric specialists? Or will these teens continue to take their health issues in stride, further incorporating that CHD card into their lives as they see fit. Of note is that the majority of teens in this study did see themselves as normal and in conversations about the aspects of their lives that make them normal, they in turn shared with us their perspectives on the quality of their lives.

Physical activity.

The one situation discussed most frequently by the teens where they felt different from their peers, was when they talked about their physical activity levels. Although few of the teens spoke of actual physical activity restrictions (3/10 teens), only four of the teens were actively involved in physical activities on a regular basis. The activity restrictions placed on the three teens were not well-defined and in some cases different from other teens in our study with similar sequelae. Of the two teens taking Coumadin, one was afraid of participating in any sports, while the other admitted to needing to be careful but saw the worst outcome of an injury being a bigger bruise. Other reasons given for a change in physical activity were laziness, busy parents (unable to do all the driving necessary), and changes made to the way teams were picked. Along with all these reasons however there was a subtext within which I heard teens saying that their ability to keep up, their fear of a worsening heart condition and changes to their health status as they grew up, were in actuality also a part of the decision to withdraw from more formalized physical activities. Going back to analogy of the CHD as a playing card, it seemed as though at times the teens felt that the CHD card needed to be played to get them out of an activity for which they had no interest in the first place. At other times, the CHD card was withheld but the decision not to play a sport or participate in gym class was related to the above mentioned factors.

Adolescence is a period of time in which teens want to fit in with their peers. It is also a time where they begin to strike out on their own, making decisions for themselves that have an effect on their health status. When the teens in our study made the decision to bypass physical activity opportunities was this due only to wanting to fit in or in some cases, was it due to a lack of knowledge? In one teen’s case, the decision to stay away from activities such as swimming or gym class was related in large part to being hit in the head and subsequently developing a large clot (due to her medication). With the appropriate knowledge and some specific guidelines, would this teen have been likely to remain more physically active? In our study the teens did not speak of firm guidelines in terms of what they were allowed or able to do physically and instead relied on their own understanding of their bodies to determine their exercise capacity. For example one young teen spoke of taking breaks based on how he felt and that this may have occurred after running for an hour. For the most part, the teens in our study were left to decide for themselves when they had reached that point of ‘too much’ and as such made the decision to stop.

Teens in this study also referred to their laziness as a reason for a change to their physical activity levels. In their study on types of physical activity teens participate in, Bélanger, Gray-Donald, O'Loughlin, Paradis, and Hanley (2009) found an overall decrease in physical activity occurred during adolescence, related to factors such as the intensity and the format of the activity. Although the teens in our study evidently had other factors relating to their decreased physical activity levels, they like their peers would experience drops in physical activity levels related to the same factors. Having the added stressor of not knowing how much activity is too much from a cardiac perspective would further compound this issue, giving them one more reason to shy away from physical activity.

Quality of life overall is affected in part by an individual's ability to participate in physical activities. The teens in this study most frequently reported their physical functioning abilities as being the one thing that set them apart from their peers. Given this, it is logical to suppose their QOL would be affected by this as well, although whether or not this is true goes beyond the scope of this study. In a previous research study with adult CHD patients Loup et al. (2009) found this was not the case and in fact these adults were able to "adapt their way of living and avoid certain types of exercise and sport" (p. 109) that made their symptoms increase and as such did not feel their QOL was affected by their abilities to perform physical activities. In a study seeking to understand how the self-reported exercise capacity in adults and adolescents with CHD related to their actual exercise capacity, Gratz, Hess and Hager (2009) found that the two groups studied were in fact poor reporters of their exercise capacity. The authors' provocatively claimed that one should "Never trust a patient pretending a good exercise capacity" (p. 503). They also noted that the knowledge deficit that I have referred to as well may lead to over protectiveness on the part of parents causing over or under exertion on the part of the patients themselves which in turn can lead to false reporting. Failing to understand the ways in which 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.

Transition.

The adolescent population is unique in that it represents a group of individuals who seek an increase in their sense of independence: a "critical aspect of development during adolescence" (Kyngäs, 2003, 745). Berntsson, Berg, Brydolf and Hellström (2007) point out that the transition from childhood to adulthood involves "a change in body, cognitive development, liberation, the need to test limits and examining one's identity" (419). Coping with a chronic illness such as CHD may result in increased difficulties in achieving this sense of independence because as Kyngäs points out, adolescents often must learn to rely less on their parents to help them take care of themselves. Higgins and Tong (2003) point out that although CHD is not a hindrance to achieving independence in adolescence, it can modify the progression towards it (independence).

This last point helps set the stage for understanding the need to set up programs that address transition issues for teens. The insightful comments and the extensive knowledge base (concerning their conditions) possessed by the majority of our participants has illustrated that these teens are well set-up to make the transition into adult care but that some measures must be set up to help this process occur smoothly. Setting up a transition program is important for teens and as Higgins and Tong (2003) pointed out, a “hallmark of independence” (p.93) for teens with CHD is moving from the care of the pediatric cardiologist to that of the adult cardiologist. Setting up a program for the type of teens interviewed for this study is evidently necessary but must be done with due care.

The teens in our study spoke of how beneficial it was for them to talk to someone other than a parent about their life growing up with CHD. As has been shown throughout this paper, thoughts about their overall QOL were on the minds of these teens and as such indicate that talking to them about how the quality of their life is affected by their CHD was both relevant and important. At their present stage of development, these teens are looking to engage in some formal decision making activities and as such any program of care related to helping teens transition must contain a component of choice to help them through this period. The idea is to create a program that involves a transition of care as opposed to just a transfer of care from one specialty group to another as this will be most beneficial to all involved in the care of teens with CHD (i.e., the teens themselves, their parents, and their health care practitioners). Acknowledgement of the teen point of view is essential when setting up any program that will affect their overall QOL.

Limitations

Several limitations are of note in this study. 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 QOL was affected by their overall condition. Secondly, all interviews were not conducted by the same interviewer and as such, differences in lines of questioning and an ability to build on knowledge gained from past interviews was not always possible.

In line with this is the knowledge that my own involvement in conducting the actual interviews and their subsequent transcription was minimal and as such limited me in terms of getting a full picture of the teens interviewed. The advantage of being present for the interview itself is that one is in an undeniably better position to get a first person account of the phenomena at hand. Although I recognize this as a limitation in this study, I do feel that I was able to overcome this in part by having access to both oral and written versions of the interviews, combined with countless discussions with the interviewers (yet another, more informal data source). This in turn enabled me to interpret and thus construct valuable ideas about the data collected.

Implications for Clinical Practice

Evidently, the need exists for a transition program in Alberta for teens that have grown up with CHD. Building on the knowledge gained from this study and others like it will enhance the ability to understand what issues must be considered when building such a program. Teens do talk about and relate to issues about the quality of their life but this is not done in an overt manner. Their understanding of quality of life incorporates the concrete grade nine definition of a life that is either ‘good’ or ‘bad’ so when working to develop a program that addresses QOL issues it is important to be aware of how the language used to get at the important issues may impact on the overall knowledge gained.

Discussions with team members involved in this study have led to the idea of creating an opportunity for Alberta teens (such as those in our study) with CHD to participate in a weekend retreat where topics such as medication management, physical activity guidelines, sexual education, and alcohol and drug use are discussed. In this type of setting, the hope would be that teens would join together in a friendly non-threatening environment to learn more about CHD and how it will factor into their lives as they mature. Creating an opportunity to discuss topics of relevance to the teens in their everyday lives will hopefully empower the teens and encourage them to continue to take steps towards becoming independent young adults.

As well it will be important to continue to acknowledge and encourage the input from the teens themselves about how they see their health futures unfolding. These teens are already involved with decision making when it comes to deciding when to play the CHD card and when to hold back on it, thus choosing to situate their CHD in either the foreground or background of their lives. Any future programs developed would do well to heed this knowledge or otherwise risk putting their programs in jeopardy due to a lack of teen-centered initiatives.

Implications for Education

As providers of care to this unique group of individuals, we have a responsibility to continue to monitor and understand the issues facing teens today. Helping build and develop programs that address the process of normalization, physical activity levels, and transition of teens to adult care will help create positive outcomes for these teens with whom we have been intimately involved with from birth. Loss to follow-up is a serious concern for this group of individuals, especially when on the surface, there appears to be no need for further care (i.e., no noticeable change in their symptoms, and no medications being taken). Helping the health care practitioners in charge of their care grasp the issues of concern with teens will help create harmonious relationships between health care practitioners and teens and ultimately lead to better health outcomes.

Implications for Future Research

There are several areas that require further research before the implementation of a transition program can occur. The voices of the parents were specifically left out of this project in order to get at what the teens themselves saw as pertinent issues relating to QOL and having grown up with CHD. Any project involving teens must incorporate the views of the parents because they are the ones immediately responsible for helping teens transition to adulthood. Soliciting their points of view about the same topics discussed herein will fill the gaps and help address any inconsistencies in reporting that may have come from the teens.

Additionally, data was collected from the teens in the form of the PedsQL and PedsQL cardiac module. This information needs to be analyzed and then compared with the qualitative data provided by the teens to ascertain whether or not what they reported in the interviews correlates with the data they provided in the surveys.

Another area for future research involves continuing to investigate the concept of quality of life in an effort to understand both what QOL is and what it is not. The dimensions that encompass quality of life (such as psychosocial, physical, emotional) are varied and their inclusion (or exclusion) from a QOL tool is not always clearly understood. Decision making with regards to which dimensions to include in a study, should occur once an understanding of what QOL means to a specific population is understood. The pediatric CHD population is unique and it follows that QOL tools should be representative of what quality of life means to these individuals.

Conclusion

Teens who have grown up with CHD are in many ways similar to their peers. The fact that they have a congenital heart defect for which no cure exists at present 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 and as such a discussion surrounding the issues that enable a teen to feel like they fit in (such as grades, scars, employment, physical activity), will create opportunities for health care practitioners to address QOL issues. Deciding when to play their CHD card and thus situate CHD in the foreground or background of their lives has enabled these teens to best cope with the obstacles life has presented them with. In a discussion about QOL with teens, understanding this concept is foremost if one is to get at the core of the issues at hand.

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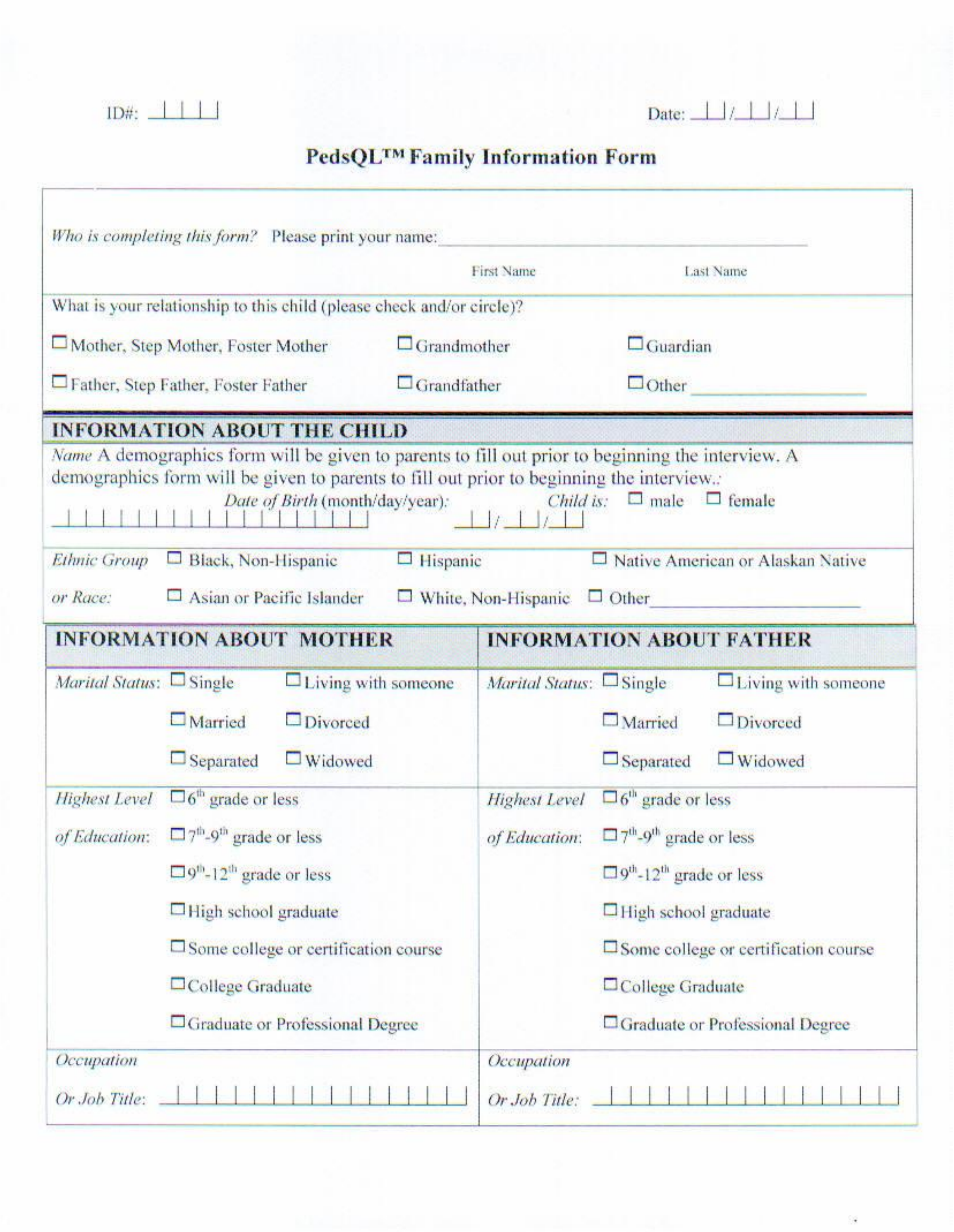
Appendix A

Guiding Questions

1) What's a typical day like for you right now? [Warm up question. Probes: What kinds of things do you enjoy doing? How's school? Do you enjoy your friends? How are things in your family? Are you easy to live with?]
2) I read an article that talked about youth with heart problems having a "less-than-ordinary" life – what do you think of that? What does an "ordinary life" look like to you?
3) On a typical day, what sorts of things do you do that you think might set you apart from your friends? Do you think this is related to your heart condition? Tell me how.
4) Tell me about filling out the 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?
5) Were there problems or concerns that you have that you found weren't addressed in this questionnaire? Tell me about them.

Appendix B



ID#: ____ Date: __/__/__

PedsQL™ Family Information Form

Who is completing this form? Please print your name: ____________________

First Name Last Name

What is your relationship to this child (please check and/or circle)?

☐ Mother, Step Mother, Foster Mother	☐ Grandmother	☐ Guardian
☐ Father, Step Father, Foster Father	☐ Grandfather	☐ Other ____________

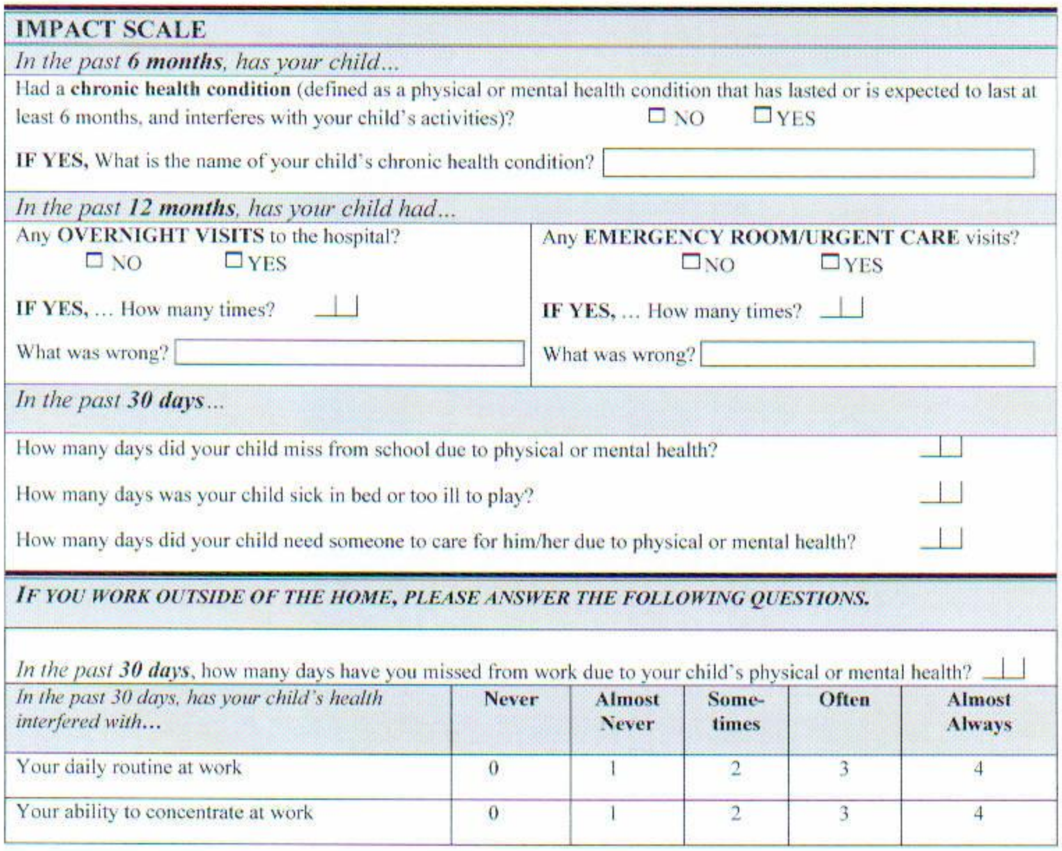
INFORMATION ABOUT THE CHILD

Name A demographics form will be given to parents to fill out prior to beginning the interview. A demographics form will be given to parents to fill out prior to beginning the interview.:

____________________ *Date of Birth* (month/day/year): __/__/__ *Child is:* ☐ male ☐ female

Ethnic Group	☐ Black, Non-Hispanic	☐ Hispanic	☐ Native American or Alaskan Native
or Race:	☐ Asian or Pacific Islander	☐ White, Non-Hispanic	☐ Other ____________

INFORMATION ABOUT MOTHER			**INFORMATION ABOUT FATHER**		
Marital Status:	☐ Single	☐ Living with someone	*Marital Status*:	☐ Single	☐ Living with someone
	☐ Married	☐ Divorced		☐ Married	☐ Divorced
	☐ Separated	☐ Widowed		☐ Separated	☐ Widowed
Highest Level	☐ 6th grade or less		*Highest Level*	☐ 6th grade or less	
of Education:	☐ 7th-9th grade or less		*of Education*:	☐ 7th-9th grade or less	
	☐ 9th-12th grade or less			☐ 9th-12th grade or less	
	☐ High school graduate			☐ High school graduate	
	☐ Some college or certification course			☐ Some college or certification course	
	☐ College Graduate			☐ College Graduate	
	☐ Graduate or Professional Degree			☐ Graduate or Professional Degree	
Occupation *Or Job Title*:	____________________		*Occupation* *Or Job Title*:	____________________	



IMPACT SCALE

*In the past **6 months**, has your child...*

Had a **chronic health condition** (defined as a physical or mental health condition that has lasted or is expected to last at least 6 months, and interferes with your child's activities)? ☐ NO ☐ YES

IF YES, What is the name of your child's chronic health condition?

*In the past **12 months**, has your child had...*

Any **OVERNIGHT VISITS** to the hospital? ☐ NO ☐ YES

IF YES, ... How many times?

What was wrong?

Any **EMERGENCY ROOM/URGENT CARE** visits? ☐ NO ☐ YES

IF YES, ... How many times?

What was wrong?

*In the past **30 days**...*

How many days did your child miss from school due to physical or mental health?

How many days was your child sick in bed or too ill to play?

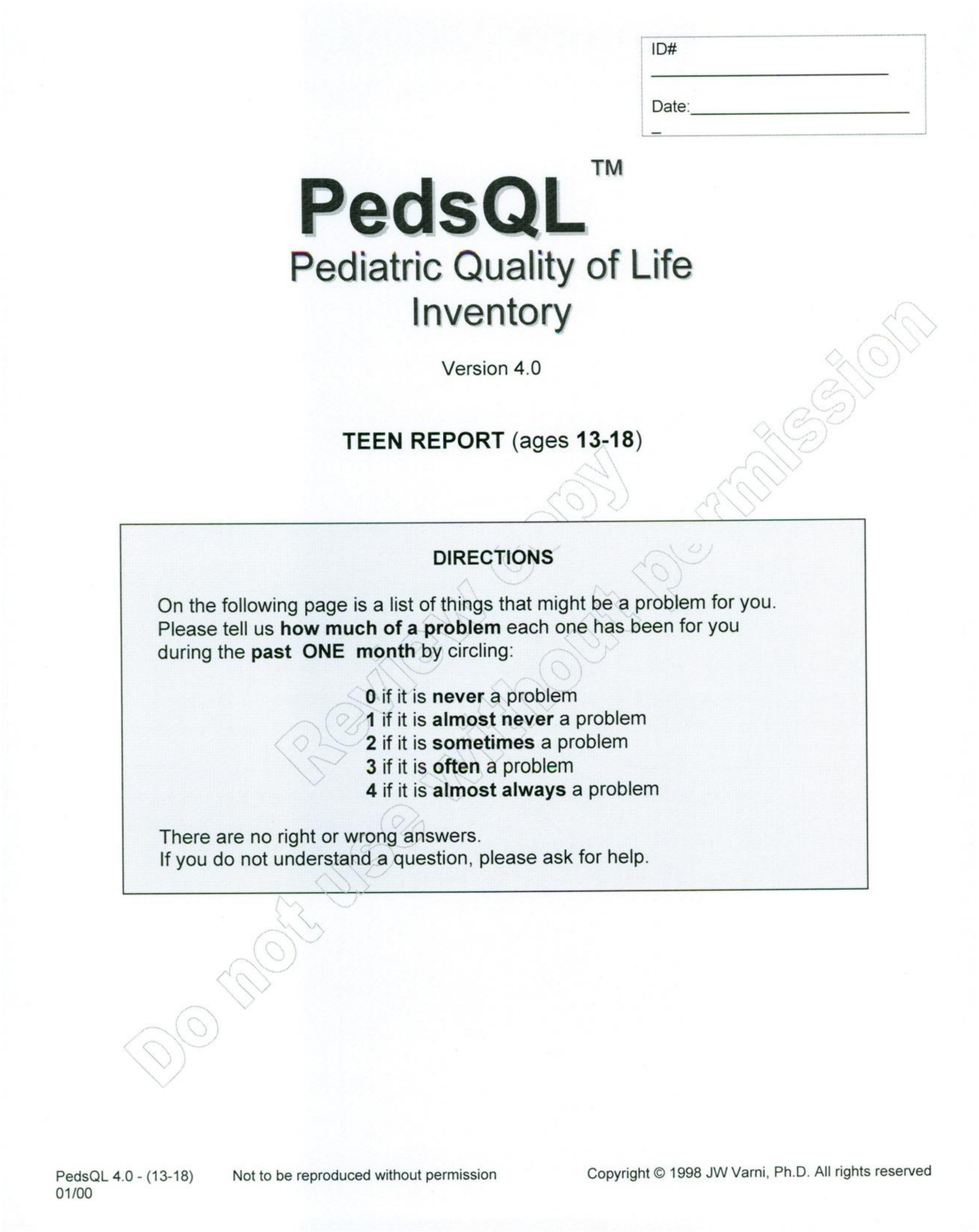
How many days did your child need someone to care for him/her due to physical or mental health?

IF YOU WORK OUTSIDE OF THE HOME, PLEASE ANSWER THE FOLLOWING QUESTIONS.

*In the past **30 days**,* how many days have you missed from work due to your child's physical or mental health?

In the past 30 days, has your child's health interfered with...	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
Your daily routine at work	0	1	2	3	4
Your ability to concentrate at work	0	1	2	3	4

Appendix C



ID#

Date:

PedsQL™

Pediatric Quality of Life Inventory

Version 4.0

TEEN REPORT (ages **13-18**)

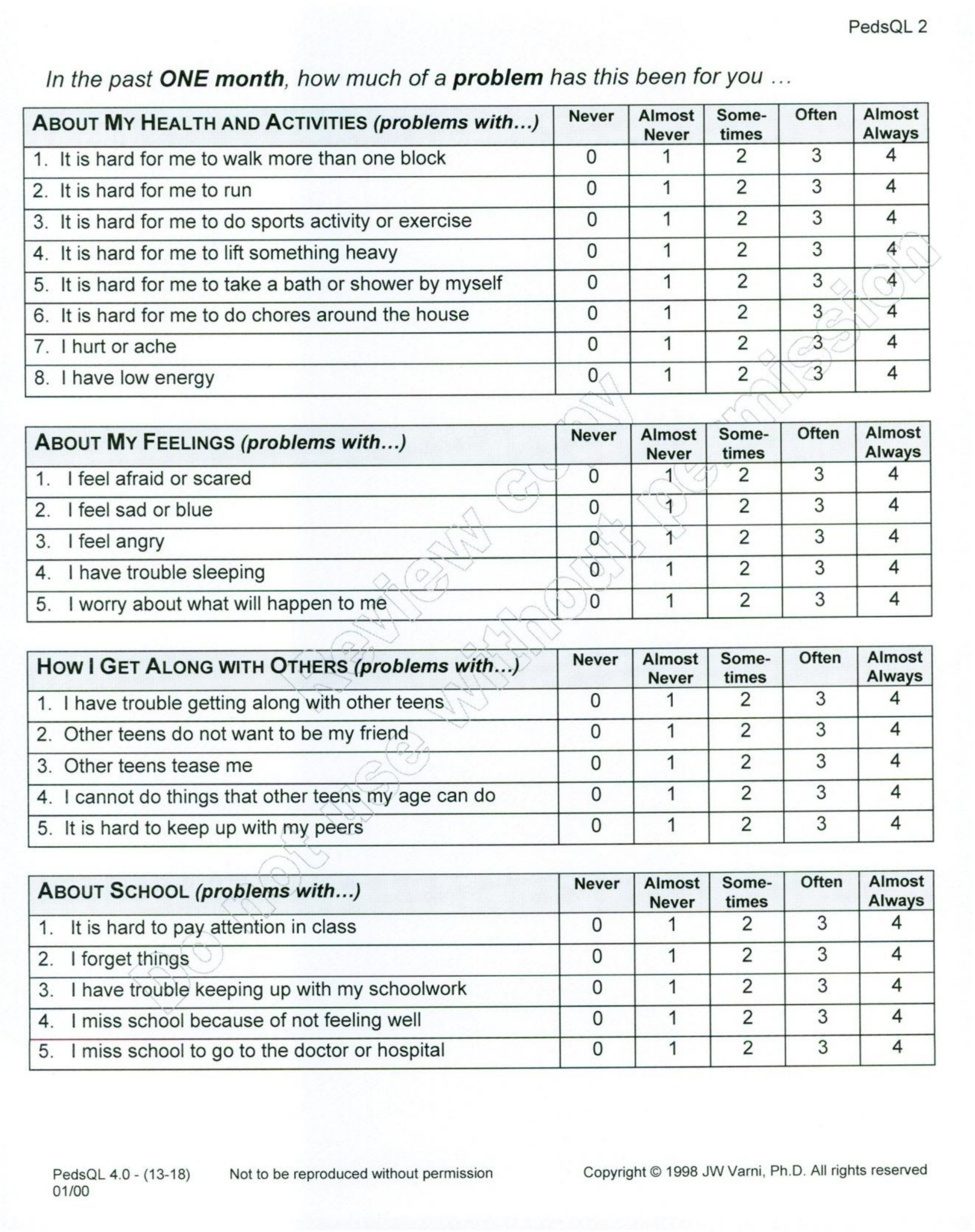
DIRECTIONS

On the following page is a list of things that might be a problem for you. Please tell us **how much of a problem** each one has been for you during the **past ONE month** by circling:

0 if it is **never** a problem
1 if it is **almost never** a problem
2 if it is **sometimes** a problem
3 if it is **often** a problem
4 if it is **almost always** a problem

There are no right or wrong answers.
If you do not understand a question, please ask for help.

PedsQL 4.0 - (13-18)
01/00



In the past ***ONE month****, how much of a* ***problem*** *has this been for you …*

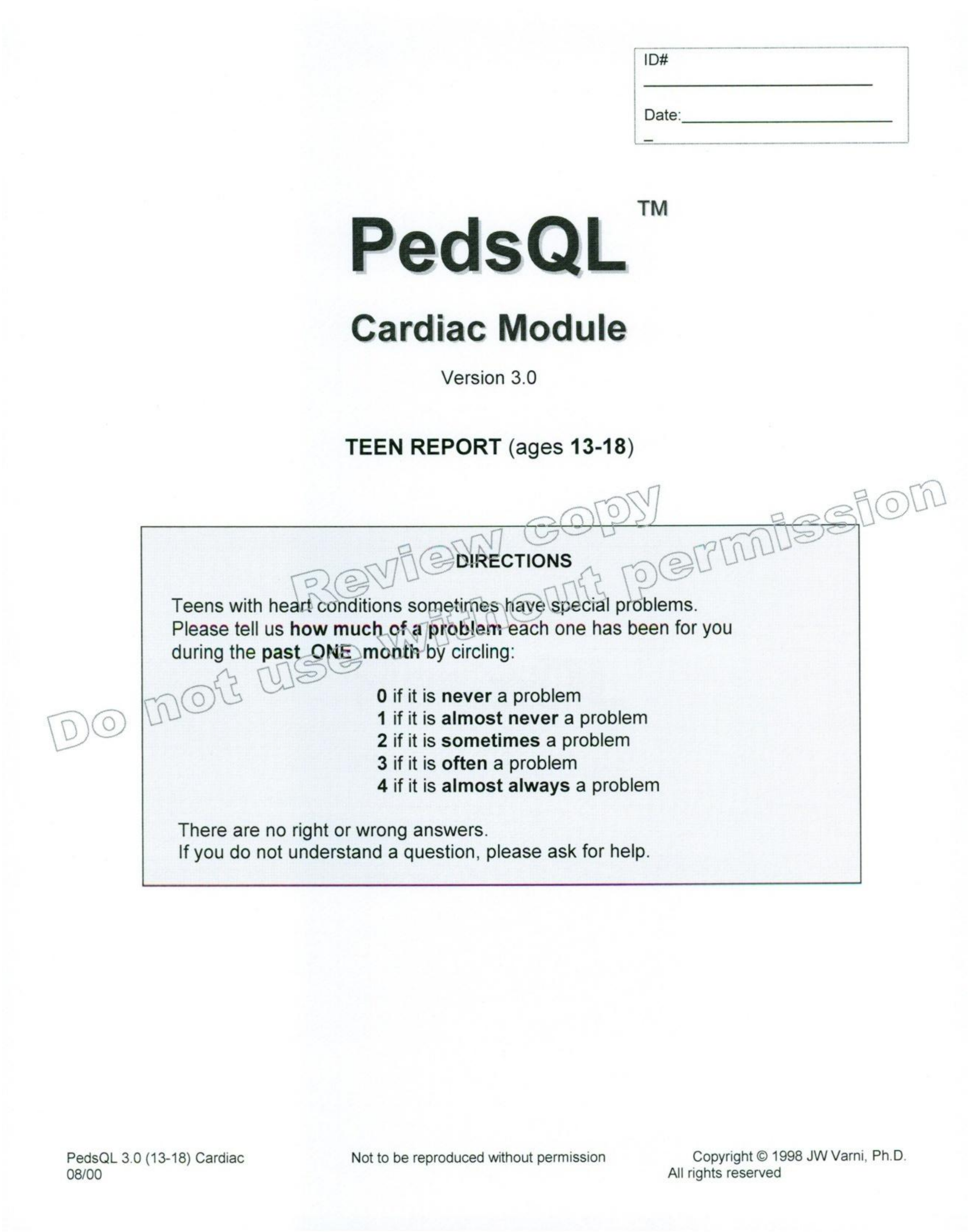
ABOUT MY HEALTH AND ACTIVITIES ***(problems with…)***	Never	Almost Never	Some-times	Often	Almost Always
1. It is hard for me to walk more than one block	0	1	2	3	4
2. It is hard for me to run	0	1	2	3	4
3. It is hard for me to do sports activity or exercise	0	1	2	3	4
4. It is hard for me to lift something heavy	0	1	2	3	4
5. It is hard for me to take a bath or shower by myself	0	1	2	3	4
6. It is hard for me to do chores around the house	0	1	2	3	4
7. I hurt or ache	0	1	2	3	4
8. I have low energy	0	1	2	3	4

ABOUT MY FEELINGS ***(problems with…)***	Never	Almost Never	Some-times	Often	Almost Always
1. I feel afraid or scared	0	1	2	3	4
2. I feel sad or blue	0	1	2	3	4
3. I feel angry	0	1	2	3	4
4. I have trouble sleeping	0	1	2	3	4
5. I worry about what will happen to me	0	1	2	3	4

HOW I GET ALONG WITH OTHERS ***(problems with…)***	Never	Almost Never	Some-times	Often	Almost Always
1. I have trouble getting along with other teens	0	1	2	3	4
2. Other teens do not want to be my friend	0	1	2	3	4
3. Other teens tease me	0	1	2	3	4
4. I cannot do things that other teens my age can do	0	1	2	3	4
5. It is hard to keep up with my peers	0	1	2	3	4

ABOUT SCHOOL ***(problems with…)***	Never	Almost Never	Some-times	Often	Almost Always
1. It is hard to pay attention in class	0	1	2	3	4
2. I forget things	0	1	2	3	4
3. I have trouble keeping up with my schoolwork	0	1	2	3	4
4. I miss school because of not feeling well	0	1	2	3	4
5. I miss school to go to the doctor or hospital	0	1	2	3	4

Appendix D



ID# ____________________

Date: ____________________

PedsQL ™

Cardiac Module

Version 3.0

TEEN REPORT (ages **13-18**)

DIRECTIONS

Teens with heart conditions sometimes have special problems. Please tell us **how much of a problem** each one has been for you during the **past ONE month** by circling:

- **0** if it is **never** a problem
- **1** if it is **almost never** a problem
- **2** if it is **sometimes** a problem
- **3** if it is **often** a problem
- **4** if it is **almost always** a problem

There are no right or wrong answers.
If you do not understand a question, please ask for help.

PedsQL 3.0 (13-18) Cardiac
08/00

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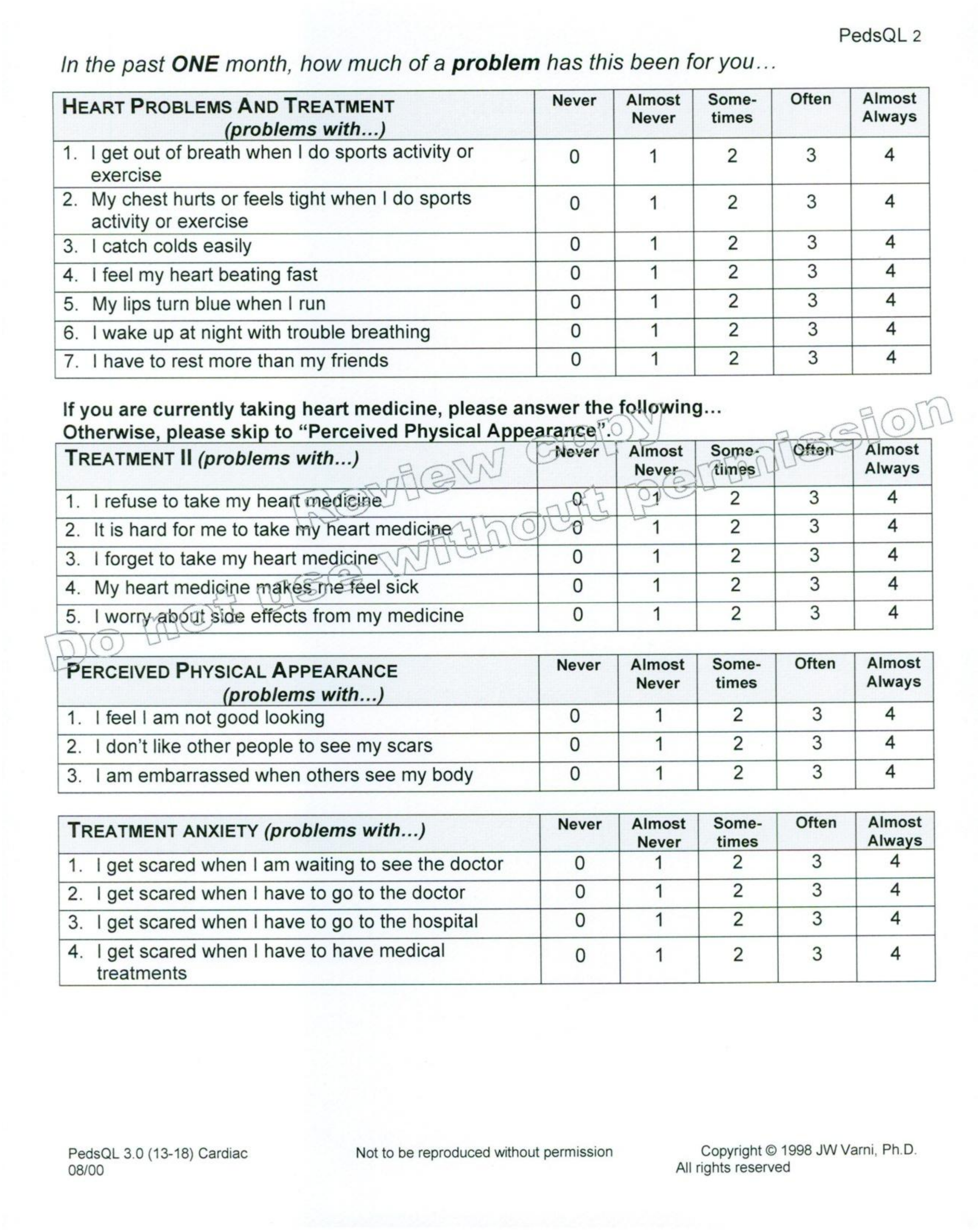


PedsQL 2

*In the past **ONE** month, how much of a **problem** has this been for you…*

HEART PROBLEMS AND TREATMENT ***(problems with…)***	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
1. I get out of breath when I do sports activity or exercise	0	1	2	3	4
2. My chest hurts or feels tight when I do sports activity or exercise	0	1	2	3	4
3. I catch colds easily	0	1	2	3	4
4. I feel my heart beating fast	0	1	2	3	4
5. My lips turn blue when I run	0	1	2	3	4
6. I wake up at night with trouble breathing	0	1	2	3	4
7. I have to rest more than my friends	0	1	2	3	4

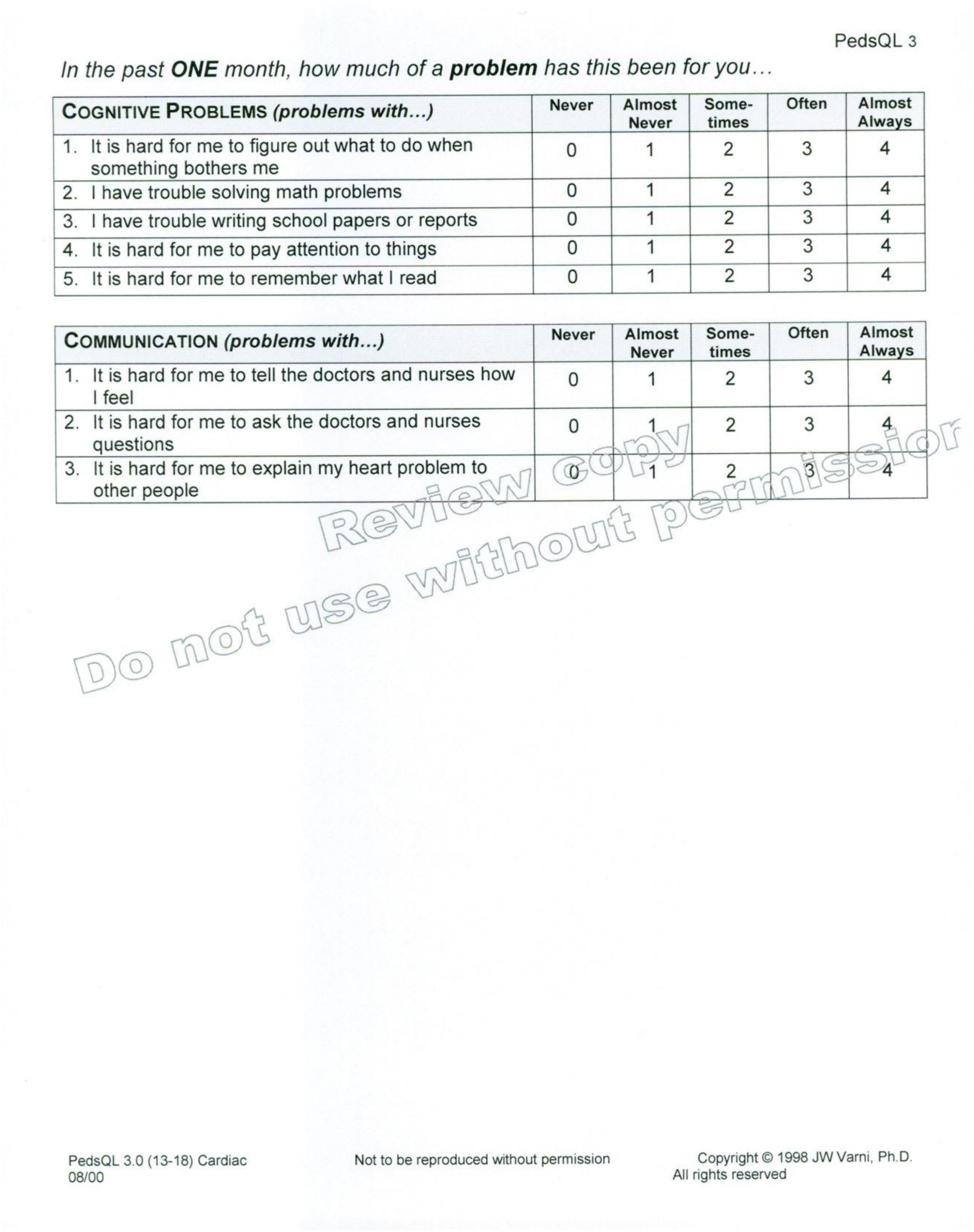
If you are currently taking heart medicine, please answer the following…
Otherwise, please skip to "Perceived Physical Appearance".

TREATMENT II ***(problems with…)***	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
1. I refuse to take my heart medicine	0	1	2	3	4
2. It is hard for me to take my heart medicine	0	1	2	3	4
3. I forget to take my heart medicine	0	1	2	3	4
4. My heart medicine makes me feel sick	0	1	2	3	4
5. I worry about side effects from my medicine	0	1	2	3	4

PERCEIVED PHYSICAL APPEARANCE ***(problems with…)***	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
1. I feel I am not good looking	0	1	2	3	4
2. I don't like other people to see my scars	0	1	2	3	4
3. I am embarrassed when others see my body	0	1	2	3	4

TREATMENT ANXIETY ***(problems with…)***	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
1. I get scared when I am waiting to see the doctor	0	1	2	3	4
2. I get scared when I have to go to the doctor	0	1	2	3	4
3. I get scared when I have to go to the hospital	0	1	2	3	4
4. I get scared when I have to have medical treatments	0	1	2	3	4

PedsQL 3.0 (13-18) Cardiac
08/00



PedsQL 3

*In the past **ONE** month, how much of a **problem** has this been for you…*

COGNITIVE PROBLEMS *(problems with…)*	Never	Almost Never	Some-times	Often	Almost Always
1. It is hard for me to figure out what to do when something bothers me	0	1	2	3	4
2. I have trouble solving math problems	0	1	2	3	4
3. I have trouble writing school papers or reports	0	1	2	3	4
4. It is hard for me to pay attention to things	0	1	2	3	4
5. It is hard for me to remember what I read	0	1	2	3	4

COMMUNICATION *(problems with…)*	Never	Almost Never	Some-times	Often	Almost Always
1. It is hard for me to tell the doctors and nurses how I feel	0	1	2	3	4
2. It is hard for me to ask the doctors and nurses questions	0	1	2	3	4
3. It is hard for me to explain my heart problem to other people	0	1	2	3	4

PedsQL 3.0 (13-18) Cardiac
08/00

Appendix E

Coding Structure

A: **Quality of Life**

- A1: General Life Satisfaction

B: **Adolescent Specific View**

- B1: Independence Seeking Behaviours – need to test limits and examine one's identity
- B2: Adolescent Perspective – any mention of differing points of view (different from their parents)
- B3: Over protectiveness from parents
- B4: Attaching Relevance & Meaning to CHD & QOL
- B5: What teens find most/least helpful from parents/what they need most from them right now

C: **Psychosocial Concerns**

- C1: Coping
- C2: Limitations
- C3: Exclusion
- C4: Discrimination & Bullying
- C5: Hope for Life Improvement

D: **Physiological Concerns**

- D1: Career Choices: for example one that does not involve manual labour; police force;
- D2: Impairment: decreased stamina and limited ability to keep up; breathlessness; decreased endurance and pace; more frequent rest periods
- D3: Life Choices: smoking, drinking

E: **Sensitizing Concepts** – From the literature

- E1: Dilemmas of Normality – perceiving oneself as normal, equal to and like everyone else, or as different, deficient and less than perfect and thus at risk for being an outsider
- E2: Dilemmas of Disclosure
  - E2-1: parent disclosure
  - E2-2: disclosure of teens with other teens

- E3: Challenges of Social Integration vs. Social Isolation
- E4: Challenges of Dependence vs. Independence
- E5: Challenge of Uncertainty
- E6: Strategies for Coping

F: **Knowledge of Physiological Concerns**

- F1: Knowledge of Heart Defect
- F2: Follow-Up Needs
- F4: Symptoms that indicate a worsening of the heart condition.

G: **QOL: Generic**

- G1: I feel scared, afraid, sad/blue, and angry; I have trouble sleeping; I worry about what will happen to me
- G2: Getting Along with Others: I have trouble getting along with other teens; others don’t want to be my friend/tease me; I can’t do things others my age can; I find it hard to keep up
- G3: School – Hard to pay attention; forget things; trouble keeping up with school work; miss it b/c of not feeling well; miss it for doctor’s appointments or to go to the hospital

H: **QOL – Cardiac Module**

- H1: Heart Problems & Treatment: get out of breath with sports activity/exercise; chest hurts with sports activity/exercise; catch colds easily; heart beating fast; lips turn blue; wake up at night with trouble breathing; rest more than friends
- H2: Medicine: refusal to take it; hard to take it; forget to take it; makes me feel sick; side effects worry me
- H3: Perceived Physical Appearance: feel not good looking; don’t want others to see scars; embarrassed when others see my body
- H4: Treatment Anxiety: scared to see doctor; scared to go to doctor; scared to go to hospital; scared to have medical treatments
- H5: Cognitive Problems: hard to figure out what to do when something bothers me; trouble with math; trouble with writing papers and reports; hard to pay attention; hard to remember what I read

- H6: Communication: hard to tell doctors and nurses how I feel; hard to ask doctors and nurses questions; hard to explain heart problem to others

I: **Quotable Quotes**

J: **Trust Concepts**

- J1: With HCP's/in the hospital setting
- J2: With the interview – building a trusting relationship throughout the interview
- J3: Trust relationship with parents