SCHOOL CHILDREN WITH CONGENITAL HEART DISEASE: QUALITY OF LIFE AND POLICY IMPLICATIONS

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ABSTRACT

Congenital heart disease is one of the most common pediatric chronic illnesses that can have an impact on the lives of affected children and their families. Despite the growing number of school-age children who live with congenital heart disease, few researchers have investigated the lives and well-being of these children and their families. The present study examined the school experiences, quality of life, and recommendations of children and families who live with congenital heart disease. Semi-structured interviews were conducted with 76 participants including school-age children who have congenital heart disease and their parent(s) or guardian(s). Results indicate that to optimize the school experiences of children and families who live with congenital heart disease, medical and school professionals who work with and support these individuals must consider what we term the Five C's: communication, confidentiality, consistency, competence, and compassion.

INTRODUCTION

Congenital heart disease (CHD) is any "structural or functional heart disease that is present at birth, even if it is discovered much later" (Hoffman, 1990, p. 26). Traditionally, children born with serious forms of CHD rarely survived beyond childhood (Gudmundsdottir et al., 1996). Today, eight of every 1000 children born alive have congenital heart defects (Saenz, Beebe, & Triplett, 1999), and due to significant advances in diagnosis, management, medical technology, medicines, and surgical procedures, many of these children are living longer (Davis, Brown, & Bakeman, 1998; Goldberg, 1990; Mescon & Honig, 1995; Perloff, 1991). In fact, approximately 85% of individuals born with heart deformities live to adulthood (Perloff, 1991).

The enhanced survival of children born with CHD has led to a growing group of individuals and families that face numerous challenges and have unique needs (Tong & Sparacino, 1994). Children with CHD can experience extensive psychological difficulties (Carr, 1976) that negatively impact their development. For instance, many children with CHD experience embarrassment, self-consciousness (Bricker & McNamara, 1983), anxiety, and medical fears (Gupta, Mitchell, Giuffre, & Crawford, 2001). Additionally, adolescents who have severe heart defects can have overanxious disorder, separation anxiety, dysthymic disorder, attention deficit disorder, and conduct disorder (Bjornstad, 1995).

Clearly, children and adolescents who live with CHD have unique care needs that must be attended to so their development is optimized (Bowen, 1985). School is an environment that provides students with opportunities to learn, interact with peers and adults, and experience success (Davis, 1989; Perrin & Gerrity, 1984; Youssef, 1988). School, however, can be a place where children experience the restrictiveness of their illness (Hobbs, Perrin, & Ireys, 1985). For instance, children who have serious forms of CHD can undergo numerous operations or be hospitalized repeatedly (DeMaso, Beardslee, Silbert, & Fyler, 1990) and thus, frequently miss school and have reduced social interaction. These experiences can negatively impact intellectual performance (Masi & Brovedani, 1999) and lead to lowered self-confidence and feelings of rejection (Hobbs et al., 1985) and isolation (Bricker & McNamara, 1983). Furthermore, children with chronic illnesses often have psychosocial difficulties that can disrupt their functioning and development (Sexson & Madan-Swain, 1993), and children who have CHD may experience regression, school phobia, and behavioral disturbances (Bricker & McNamara, 1983).

In the school environment, the development of a child who has a chronic illness is greatly affected by the attitudes, behaviors, and actions of his/her teachers (Nevile & Roberts, 1999). For instance, by facilitating play, learning, and peer relationships, teachers can support children in experiencing mastery and optimizing their development (Mescon & Honig, 1995). Teachers and school professionals must be prepared, therefore, to meet the needs of children who live with chronic illnesses such as CHD (Nevile & Roberts, 1999; Roberts, 2000; Roberts, Pettifor, Cairns, & DeMatteo, 2000). Lynch, Lewis, and Murphy (1993) indicate, however, that "despite the increase in the numbers of children with chronic illness and the new challenges they present, few studies have investigated the issues that schools and families encounter in their efforts to meet these children's needs" (p. 211).

Spirito, Stark, Gil, and Tyc (1995) suggest researchers must clearly delineate what children with chronic illness experience and identify interventions that will optimize the functioning of these children. Although research has examined the functioning and well-being of children with leukemia and diabetes, the lives and experiences of children with other chronic diseases have received little consideration (Midence, 1994). In fact, few researchers have examined how CHD impacts children, their families (Janus & Goldberg, 1997), and the school experiences of these individuals. The present study, therefore, examines the unique school experiences and quality of life of children and families who live with CHD. By conducting semi-structured interviews with children who have CHD and their parents, the present study identifies the quality of life, experiences, concerns, and recommendations of these individuals to educate the academic, medical, and educational communities who work with and support them.

METHOD

RESEARCH DESIGN

The first author, in collaboration with the Department of Pediatrics at the Victoria General Hospital, conducted a phenomenologically-informed study (Creswell, 1998; Colaizzi, 1978; Giorgi, 1985; Moustakas, 1994; Polkinghorne, 1989; Tesch, 1990) to identify the school experiences of children and families who live with CHD and to ascertain how these families think schools can best assist students and families affected by CHD. The purpose of phenomenology is to collect descriptions of an experience (Valle & Halling, 1989). These descriptions are thematically analyzed to identify the

meaning of an experience and to provide understanding of the participants' common experiences. This rigorous qualitative methodology was chosen to provide contextual understanding of the participants' emotions, experiences, and perceptions.

PARTICIPANTS

Twenty-nine families with school-age children who have CHD participated in the present study. In all but five families, the children, along with parent(s)/guardian(s), participated in the interviews. Of the 76 people interviewed, 24 were children with CHD, 28 were mothers, 10 were fathers, and five were other family members who acted as guardians and were directly involved with the school experiences of the affected child. All participants resided in British Columbia, Canada. Participants were recruited from hospitals and a family support network, and they were purposefully selected to represent a diverse selection of ages, genders, and forms of CHD. Of the 29 children with CHD whose families participated, 13 were male, 16 were female, and all were between five and 17 years of age. To ensure full informed consent, each participant family was sent an informed consent form that described the purpose of the study, the benefits of participation, and information about anonymity and confidentiality prior to their interview.

DATA COLLECTION

Semi-structured interviews were conducted with each participant family to develop a comprehensive understanding of the participants' experiences (Roberts & Cairns, 1999). During each tape-recorded interview, the researcher posed questions to elicit information on the CHD school experience and quality of life (see Appendix). These questions were followed by prompts based on a quality of life theoretical framework (Keith & Schalock, 1994) that focuses on general feelings of satisfaction, well-being, social belonging, and empowerment (See Figure 1).

DATA ANALYSIS

Once data collection was complete, the interviews were analyzed using a procedure developed by Colaizzi (1978) and modified by Roberts and Cairns (1999). The essential elements of this procedure are:

1. repeatedly listening to the interview tapes to gather a sense of the interviews' meanings;
2. typing each interview verbatim;
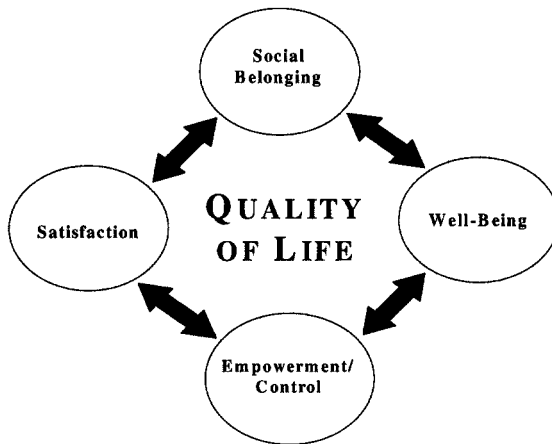3. extracting significant statements from each interview transcript; and,

Figure 1.

Roberts and Cairns (1999) pictorial representation of Keith and Shalock's (1994) QOL model.

4. formulating statements of meaning and/or themes from these extracted statements.

After each interview was typed and themes were formulated, each transcript and first level analysis was returned to its respective participant family. A second interview was then conducted with each participant family to ensure accuracy of the typed transcript and thematic representations, and to gather any additional information or insight.

In the present study, a theme was included if it was common to a minimum of 70% of the participants interviewed. Similar themes were grouped together to form clusters and labeled according to their most central meaning. Similar clusters were sorted into categories and titled based on their principal meaning. The major categories and thematic structure were then "integrated into an exhaustive description of the investigated topic" (Colaizzi, 1978, p. 61).

Textual analysis was assisted with NVivo (Bazeley & Richards, 2000), a qualitative data analysis program. This program was designed to support analytical and synthetical tasks, and therefore, was ideally suited for this project. Moreover, the rapid search, retrieval, and browsing abilities of this program facilitated the analysis procedure described above.

FINDINGS

Across participants, themes emerged in five key areas: 1) communication, 2) social belonging, 3) living with risk and uncertainty, 4) complexity of medical condition, and 5) school experiences. These thematic categories and their respective theme clusters are presented in Table 1 and described below.

COMMUNICATION

The theme clusters and supporting themes that comprise the thematic category, "Communication," are offered in Table 2. The clusters are comprised of themes that address three issues: home-school communication, within-school communication, and relay of medical information. During the interviews, participants described what worked well and what was problematic in communication between themselves and school staff. Whereas several participants were happy and satisfied with the communication that occurred with school personnel, others were frustrated and concerned by communications problems they encountered. As such, many participants thought improvements could be made. The following quotes represent the different views and experiences of the participants:

> I find the school really good to deal with, for the most part pretty much everyone will listen . . .—Mother of 9 year old girl

> . . . the door is always open into [the principal's] office and the teacher's so there's communication.—Mother of 11 year old girl

> They were always willing to talk but they weren't going to change anything for one child when they had 29 others in the class.—Mother of 12 year old girl

> Yeah but I didn't understand why they didn't know because I had just gone through this with the counsellor and the counsellor was supposed to get it to all the teachers and obviously people were not reading their memos, but I just didn't have time to go to each individual teacher.—Mother of 12 year old boy

> We were feeling kind of in a state of limbo because we didn't know exactly what was going on—we had bits of information and not enough and it was really scary there for a while.—Mother of 11 year old boy

> The other thing that I think is important, they have done this, with her concurrence, that they have kind of presentations to the class about hearing problems or heart problems without, kind of making her the target, but everybody sort of knows who it's about so the kids are all aware of what can be wrong with a heart, or ear or and then they understand her particular, personal problems from the standpoint of a general awareness of that.—Father of 11 year-old girl

TABLE I
Thematic Categories and Theme Clusters Found Across Participants

Categories				
Communication	Social Belonging	Living With Risk and Uncertainty	Complexity of Medical Condition	School Experiences
Clusters Within Each Category				
Home-School Communication	Social Belonging of Children	Surgery and Medical Condition	Nature of Condition	Compassion and Understanding
Within-School Communication	Social Belonging of Parents	School Related Uncertainties	External Manifestations	School Designations and Services
Relay of Medical Information		Parental Response to Uncertainty		Sense of Control at School

TABLE 2
Theme Clusters and Supporting Themes for Communication

Communication		
Home-School Communication	Within-School Communication	Relay of Medical Information
Themes Within Each Cluster		
General parent-school staff communication	Communication between teacher(s) and child with CHD	Medical information from health professionals
Parent-administrator communication	Awareness, use, and communication of information about child	Communication of medical information between home and school
Parent-teacher communication		Relay of medical information to students at school

SOCIAL BELONGING

Table 3 displays the theme clusters and supporting themes that comprise the thematic category, "Social Belonging." Children with CHD can experience numerous physical, emotional, and psychological difficulties that make it difficult for them to fit in and feel as though they belong. Participants addressed issues regarding the social belonging of children and parents. That is, they described the importance of feeling a sense of belonging at school and in their community, and some of the struggles they faced in trying to belong. For example, one family described how a grade one teacher refused to admit their child into her class, even when the child's kindergarten friends were going to be in the class. The family thought this teacher was afraid of CHD and what the legal ramifications would be if this child became seriously ill in her class. The following quotes highlight many of the issues raised by the participants:

He's got a lot of friends and he you know is fairly social, probably like any kid.—Mother of 11 year old boy

. . . initially in kindergarten, like there were parents who didn't—wouldn't invite him over because they weren't sure if he could physically [tolerate it] . . .—Mother of 7 year old boy

TABLE 3
Theme Clusters and Supporting Themes for Social Belonging

Social Belonging	
Social Belonging of Children	Social Belonging of Parents

Themes Within Each Cluster	
Friendships at school	Level of connection with school
Teasing and bullying at school	Level of connection with other parents
Not wanting to be different	
Interference with social belonging	

She just wants to be like all the other kids and it's hard to keep her focused on the need to be cognizant of her problems and deal with them.—Father of 11 year old girl

They call us runts and say "runtie, runtie, runtie, runtie."—11 year old girl with CHD

. . . the parents are very supportive of [my child] and watching out for her and when they hear their kid comes home and says "this happened to X" it gets back to me immediately.—Mother of 11 year old girl

My involvement's been more to go in and team teach with her grade one/two teacher I could go in there anytime.—Mother of 9 year old girl

Sometimes it hurts my feelings because people say [my scar is] gross.—9 year old girl with CHD

LIVING WITH RISK AND UNCERTAINTY

The theme clusters and supporting themes that comprise the thematic category, "Living With Risk and Uncertainty," are presented in Table 4. The participants raised issues on three topics: surgery and medical condition, school related uncertainties, and parental response to uncertainty. Participants described the painful challenges of living with an unstable illness and being uncertain about the future. Additionally, families described how teachers ignored or incorrectly followed pre-established safety plans when their child

TABLE 4
Theme Clusters and Supporting Themes for Living with Risk and Uncertainty

Living With Risk and Uncertainty		
Surgery and Medical Condition	School Related Uncertainties	Parental Response to Uncertainty
Themes Within Each Cluster		
Uncertain timing of surgery	Child's ability to manage at school (socially, academically)	Parental level of worry and vigilance
Uncertainty of surgical outcomes	Frequency and effects of school absences	Parental comfort level with supervision outside of home
Constant uncertainty about the stability of child's condition	Emotional well-being of child at school	

required medical attention. Shockingly, one child who experienced severe tachycardia (racing heart beat) on the playground was passed from one duty teacher to the next without being assisted. The following participant quotes emphasize many of the issues raised:

> . . . *we don't have a lot of faith that schools will react appropriately.—Father of 7 year old boy*

> *So there's not really an understanding—I haven't found in the school system—there isn't an understanding of what parents go through to leave their children there for eight hours. I just feel to leave him at school it's just terrifying for me.—Mother of 9 year old boy*

> *There's no guarantee on how long a life span [my child] may have. They don't know. He could go on to be an aspiring, you know, successful adult . . . he could live to see ten (clears throat) and it could happen that he won't be around when he's seven.—Mother of 5 year old boy*

TABLE 5
Theme Clusters and Supporting Themes for Complexity of Medical Condition

Complexity of Medical Condition	
Nature of Condition	External Manifestation
Themes Within Each Cluster	
"Invisibility" of condition	Scarring
Compounding health concerns	Individual "signs" of distress
Physical needs and limitations	Emotional manifestations
Developmental delays of child	Being tired

You know every year we wait, their techniques get better and given enough time and if we are lucky enough she makes it a few more years they can maybe even do an intermediate surgery without going open heart on her.—Mother of 11 year old girl

[My child] is exhausting herself every night to the point of tears and crying out in frustration and she works very hard at her studies.—Father of 11 year old girl

And so she'll stay home a day, and so, as we get higher up into the content level, it's going to hurt her more and more.—Mother of 9 year old girl

And so he would come home and cry everyday about going to school and not wanting to go to school and hating school.—Mother of 7 year old boy

COMPLEXITY OF MEDICAL CONDITION
Table 5 displays the theme clusters and supporting themes that comprise the thematic category, "Complexity of Medical Condition." Participants addressed themes on two topics: nature of condition, and external manifestations. The participants described the unique and diverse physical and emotional challenges that children with CHD face. Their descriptions underline the stress these challenges bring to children and parents. The following quotes highlight issues raised by the participants:

. . . it affects his breathing, his lungs. If it affects his kidney obviously it is affecting his bladder.—Mother of 5 year old boy

. . . *because of all the heart surgeries and all the stuff she's gone through, it's caused significant delays in her development.—Mother of 7 year old girl*

. . . *when I say physically, he could do it but not for any long duration. Right? So he could do it for say, five minutes, where everyone else is doing it for thirty minutes . . .—Mother of 7 year old boy*

I guess you know with invisible disabilities people don't always see what's going on and you know . . . she looks like a normal kid to most people.—Mother of 11 year old girl

I find [my child] tends to get frustrated and angry inside if he can't, you know, like he would never be able try out for the cross-country team or something.— Mother of 9 year old boy

I like sometimes I go like I go red in the face but then I have white patches on my face and my new cardiologist said that that's just me. I just, I just do that.—11 year old boy with CHD

You were a little bit self-conscious of your scar last year but I think she is sort of getting better with that.—Mother of 9 year old girl

TABLE 6
Theme Clusters and Supporting Themes for School Experiences

School Experiences		
Compassion and Understanding	School Designation and Services	Sense of Control at School
Themes Within Each Cluster		
Teacher empathy and understanding	Designation and identification of child	Child's involvement in decisions at school
Administrator empathy and understanding	Provision of services and appropriate programs	Parental involvement in advocacy and decision-making
Flexibility of educators	Adaptations and/or modifications of school programs	Parental involvement in helping out at school
Less than positive school experiences		

SCHOOL EXPERIENCES

Table 6 presents the theme clusters and supporting themes that comprise the thematic category, "School Experiences." Issues about compassion and understanding, school designation and services, and sense of control at school were identified by the participants. The participants described how important it was to feel supported. Support was often demonstrated by empathic school staff. For instance, two families described how their principal indicated he understood what it was like to be sick and the importance of their child missing a day of school if he was sick or not feeling well. Another family explained that their principal would visit their child in the hospital and that he once said he understood their situation and needs because he also had a child with a chronic illness. Support was also shown by the development and implementation of individualized programs for children with CHD, and encouraging involvement in the school. Involving children and families appears to create a sense of control that is vital when living with uncertainty and a life-threatening illness. The following quotes reflect positive views of the participants:

> The vice-principal's kind of taken-up the slack—he's more welcoming and warm and every time he sees you he asks "how's [my child]?"—Father of 11 year old girl

> And the fact too, having Mr. X as a teacher. He knows what it is like to be ill and have a heart condition. He has some empathy—he wasn't patronizing.—Mother of 11 year old boy

> . . . and to just listen to him. I think for the most part they have.—Mother of 7 year old boy

> Totally involved, I'm on the parent advisory, you know, like I do the whole PTA thing. And [my husband] like he's there everyday, he walks the kids in just to make sure you know, the field trips we're always there I go and I test kids for the teacher, we try to stay involved.—Mother of 9 year old boy

> What's been the most helpful is that special assistant—getting somebody in there to help him with his limitations.—Aunt/Guardian of 5 year old boy

> Even though I knew there was a special program for him, it still scared me to send him to school and I was lucky enough to have a very supportive family system going. But the school also had a program for him. I was comfortable in knowing that, but it's still uncomfortable sending your kid to school and not knowing if there's anything there. And I can just imagine the horror that a parent might feel putting a child like him in school and not knowing or not being

educated as to what is out there for them.—Grandmother/Guardian of 5 year old boy

Many of the participants detailed negative views and experiences such as inconsistent school experiences and policies. For instance, whereas some parents spoke of how their children were taught by board-funded tutors because they missed extended periods of school due to CHD related hospitalizations, other families were shocked to learn of such available support. The following quotes represent many of the participants' negative views and experiences:

. . . there's no follow through from year to year.—Mother of 11 year old girl

[The teacher said] "I've absolutely had nightmares about [your child] being in my class!"—Mother of 9 year old girl

I tried to make it as simple as possible—I went over it and over it and I just kept on feeling that no matter what I came up with this simplest thing to do—that was too difficult. Well, they just didn't I guess what it is is they just didn't want her there.—Mother of 12 year old girl

. . . to really direct her program in school so that it is a little more suited to her needs, to her capabilities.—Mother of 9 year old girl

No, we're going to we're going to give you all the right key words and we're going to say yes we're really hearing what you are saying and we're really understanding this but you know what, nothing is going to change.—Mother of 11 year old boy

Well, you definitely have to watch-out for your kids, that's for sure because, you know, if you don't tell the school what's going on and how your kids are feeling they, you know, the squeaky wheel gets the grease, and the other ones that are quiet don't, I find, get as much attention.—Mother of 9 year old boy

And I had to go and, and say "This is the second time this year when a substitute has forced something to happen even though my child has used her words and said 'No, I'm not allowed.'"—Mother of 9 year old girl.

GENERAL FAMILY RECOMMENDATIONS

During the interviews, families were asked to provide recommendations for schools that are preparing to meet the needs of children and families who live with CHD. Below is a concise listing of participant and researcher recommendations for school personnel:

1. Communicate all necessary information about a child to all school staff;
2. Be flexible to the unique needs of a child with CHD;

3. Listen actively to both parents and child and trust the perceptions and feelings of the child, especially regarding their own physical needs and abilities. Remember these needs and abilities may vary from moment-to moment;

4. Involve parents in their child's education and acknowledge that parents are experts on their child, particularly on signs of physical and emotional distress and fatigue;

5. Provide appropriate educational programs and services for the possible developmental delays and physical challenges of a child with CHD. For instance, organize activities such as a cross-country walk. Be sure to adapt the physical education grading system if necessary;

6. Be supportive of the emotional challenges faced by both child and family, especially in the stress the uncertainty of the illness causes;

7. Educate yourself on CHD;

8. Plan for all potential medical emergencies;

9. If necessary, create a new position in the schools or designate an individual to assist a child with chronic illness;

10. Do what you say you will do; and,

11. As frequently as possible, treat a child with CHD like a normal child.

DISCUSSION

Despite an increasing population of school-age children who have CHD, little is known about the lives of these children and their families. To provide a foundation of knowledge and direction for future research, the present study examined the school experiences and quality of life of children and families who live with CHD. Results clearly indicate that children and families who live with CHD face numerous challenges both at and outside of school. The issues and recommendations raised by participants suggest that although numerous children and families found school to be a positive and enriching environment, others experienced ethical wrongdoings and a lack of caring support, communication, and knowledgeable school personnel. When the results are considered, it becomes evident that the present study has many implications for practice and policy development within the school system. The experiences of families affected by CHD is unique and different from those who live with other childhood diseases because CHD is an unpredictable illness that forces families to live with constant uncertainty. Because parents will exhibit justifiable hypervigilance and children with CHD have unique needs, schools must be prepared to provide support and meet these diverse and changing needs. It is therefore imperative that schools educate

themselves on CHD. Moreover, if school personnel consider what we term the *Five C's* of best practice (communication, confidentiality, consistency, competence, and compassion), the school experiences and quality of life of children and families could be optimized.

COMMUNICATION

The interviewed families spoke frequently about the communication challenges they faced such as the breakdown of communication between medical professionals, administrators, teachers, and/or special student assistants. Specifically, many participants found that teachers were not made aware of medical team suggestions, that substitute teachers were not informed of a child's specific medical concerns, and that pertinent information was not passed on when a child moved from one grade level to the next. These experiences were frustrating and stressful for families and caused them to think that they needed to micro-manage their children's school day. Although no one individual or group of individuals is intentionally guilty of wrongdoing, the respect, care, and well-being of a child is compromised when communication breaks down.

CONFIDENTIALITY

In part, communication breaks down because there are insufficient school policies regarding the best and most efficient way to share private medical information. Parents explained how some teachers did not receive their son or daughter's information because of confidentiality concerns. On the other extreme, however, some parents described school professionals handling information in completely inappropriate manners. For instance, one family indicated that a teacher announced their child's medical condition to the entire class without obtaining permission to do so. Although they may believe they are acting in the best interest of a child, teachers must consider whether they lack relevant information or whether they will violate confidentiality or a child's right to privacy before they take any action.

CONSISTENCY

Issues of communication and confidentiality may be associated with inconsistent policy implementation. Many families affected by CHD participate in local support networks and through these networks, many participants learned that schools do not always provide the same support for children with CHD. Although some children receive official designations and ensuing individual education plans, others do not. Additionally, whereas some children are supported by special student assistants, others are not. Some families

note similar and extreme inconsistencies in the same school, just one year to the next. Because there is a lack of consistent and high standards of support for children and families who live with CHD, there is a problem within the education system. Although no one individual is responsible for this problem, attention must be devoted to examining and promoting the consistency of support available within and between schools.

COMPETENCE
Given the aforementioned problems, one might not be surprised that some families doubt the competence of school policies and professionals, and that these doubts threaten the trust between families and schools. Competency, however, is seriously and further questioned when school professionals mishandle medical emergencies. With the child who was left unattended in the school yard during an episode of racing heart beat, the parents wondered if the teachers involved did not want the responsibility of handing a medical emergency or if they simply had not read the safety plan. Incompetent school personnel, or expecting teachers to function beyond the limits of their training and expertise, places children at risk. However, who, if anyone, is responsible for these issues?

COMPASSION
When schools show sensitivity and compassion, the quality of life of affected families can be greatly enhanced. However, some families involved in the present study detailed how some teachers excluded their children and how students teased and harassed them about their public tachycardia attacks and open heart surgery scars. One family felt as though classroom placements were determined by a "musical chairs" method and that appointed teachers acted as though they were "stuck" with their child. Although families were upset by their children's harassment, they were most distraught over how the school ignored or mishandled the situations. Clearly, families feel little respect and care when teachers fail to control situations that place their children at risk for social isolation or emotional distress.

IMPLICATIONS FOR PRACTICE
The stress and uncertainty that families experience because of their child's chronic condition is intense and unrelenting. It is therefore unfortunate that some families face additional and unnecessary stress and insecurity because of the inappropriate practice of some school systems. It is clear that these problems must be addressed and that school policies pertaining to children with chronic illness are improved. School professionals must be aware of present

ethical dilemmas and they must be equipped with tools, such as the Canadian Psychological Association's (1995) guidelines for ethical decision-making, that can enable them to navigate through them.

The education system is becoming increasingly complex and scholars such as Hargreaves (1994) and Smyth (2001) indicate educator responsibilities are intensifying. Simply put, there is an increasing number of student needs in an environment where there are limited resources, such as time and money, to meet them (Cheng & Couture, 2000; Maxwell, 2003). It comes as no surprise, therefore, that many participants spoke of educators who were unable to meet their needs. However, results of the present study also indicate that some educators are well aware of the challenges and demands these individuals face. In fact, many participants described how their school's educators, specialists, and administrators exhibited much compassion, concern, and respect.

Educators and school psychologists should also be encouraged to discuss how the needs of students with chronic health issues can be met. Perhaps professional development opportunities should be provided to educate psychologists, teachers, administrators, and support staff about the needs of children who have chronic illnesses such as CHD. Moreover, by meeting with families who live with chronic illness and their medical professionals, school nurses, and/or school counselors, educators and psychologists will learn about their needs and become better prepared to optimize their learning and school experiences.

DIRECTIONS FOR RESEARCH

By speaking directly with children and families who live with CHD, the present study has gained foundational knowledge regarding the recommendations and school experiences of families who live with CHD. This qualitative study, however, is only an initial step in identifying the needs of families who live with CHD. Thus, future research should investigate the social-emotional impact CHD has on children, and how CHD affect's a child's learning. Moreover, researchers should examine the impact CHD has on parents and siblings.

Although recommendations for educators and school psychologists have been presented in the present study and extant literature (see Lynch et al., 1993; Mescon & Honig, 1995; Sexson & Madan-Swain, 1993, 1995), little is known about the experiences, concerns, and beliefs of teachers and administrators who are responsible for the care and education of children who have CHD. Thus, researchers must inquire into the experiences and perceptions of educators who instruct children with CHD. Such research will provide valu-

able insight into how the current education system manages the needs of children with chronic illness, and it will offer direction on how to optimize these children's school experiences, quality of life, and learning.

Although children who have different chronic illnesses may experience many of the same demands and stressors, it remains unclear how different chronic illnesses impact the school experiences of children and adolescents of different genders. Researchers, therefore, should expand on the present study and investigate the quality of life and school experiences of children and adolescents who live with other chronic illnesses. Such research will add insight into the specific learning styles, disabilities, and/or needs of children with chronic illnesses. Moreover, such research will further understanding in the area of pediatric health psychology and assist educational, medical, and helping professionals in optimizing the quality of life of families who live with chronic illness.

APPENDIX

Semi-structured Interview Guide for Parents and Children
    * *Please note that text in italics shows how the wording will be changed for children.*
State Gender & Age of Child
    I invite you to share with me your family's school experience [I'd like you to tell me about school]. Hopefully, through better understanding of what school is like for you, we will be able to offer schools some guidance on how to better accommodate, prepare and support families affected by congenital heart disease. I will invite you to share with me any other thing that comes to mind, and then follow up with questions specific to quality of life issues. Please let me know if my questions don't make sense. I will be happy to reword them.
    (* The interviewer will simplify questions as needed and as appropriate.)
Medical background
1. Can you give me a brief idea of your child's medical history?
2. When was he/she diagnosed?
3. Where do you think his/her medical severity falls on the spectrum of mild to severe?
    [*Please tell me about the medical history of your heart.*]
What is school like for you and your family?
    Does your child have a designation at the school because of his/her heart?
Satisfaction
1. How satisfied is your child with his/her current school?

2.   How satisfied are you (and your spouse) with the school?
     [*How satisfied are you with school?*]
Simplified Language:
1.   How much does your child like school?
2.   How much do you (and other members of your family) like the school?
     [*How much do you like school?*]
Well-Being:
1.   How would you judge your child's well-being at school?
2.   How would you judge your (and your spouse's) well-being when inter-
     acting with the school?
     [*How would you judge your well-being at school?*]
Simplified Language:
1.   Is your child okay when at school? (yes/no) Please tell me more.
2.   How about you? Are you (and other members of your family) okay when
     at the school? (yes/no) Please tell me more.
     [*Are you okay when at school? (yes/no) Please tell me more.*]
Social Belonging:
1.   How would you evaluate your child's social belonging at school?
2.   How would you evaluate your family's social belonging when interacting
     with the school?
     [*How would you describe your sense of belonging at school?*]
Simplified Language:
1.   Does your child have friends? Is he/she invited to birthday parties? Do
     other children tease your child? (yes/no) Please tell me more.
2.   How about you? Do you (and other members of your family) feel accept-
     ed at the school? (yes/no) Please tell me more.
     [*Do you have as many friends as you would like? Do you ever feel as though
the other kids do not accept you? (yes/no) Please tell me more.*]
Empowerment/Control:
1.   How much control does your child have over school-related issues?
2.   How much control does your family have over school-related issues?
     [*How much control do you have over school issues?*]
Simplified Language:
1.   How much "say" does your child have at school? Is your child able to
     choose or decide school things on his/her own? (yes/no) Please tell me
     more.
2.   How about you? How much say do you (and other members of your fam-
     ily) have over school issues? Does your say count? Does the school respect
     your decisions? (yes/no) Please tell me more.

[*How much "say" do you have at school? Are you able to choose or decide school things on your own? (yes/no) Please tell me more.*]
Open question:

Please share with me any other comments, suggestions, or concerns you may have regarding [*school*] your child's school situation.

What has the school done that is the most helpful?

What has the school done that has been the least helpful?

What could the school do differently that would [*be good for you*} have a positive impact on your family?

** Please note that separate interviews are offered if needed (i.e. parents without the children)

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