

The Experiences of Siblings of Children with Congenital Heart Disease

By


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B.Ed., University of Victoria, 2000

A Thesis Submitted in Partial Fulfillment of the
Requirements for the Degree of

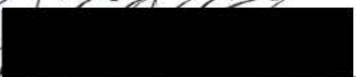
MASTER OF ARTS

in the department of Educational Psychology
and Leadership Studies


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Abstract

This qualitative study explores the lived experience of siblings of children with congenital heart disease. The participants include six school age children and their parents from Vancouver Island, British Columbia (total n = 14). Data were gathered using semi-structured interviews and were thematically analysed. Findings of the inquiry indicate that children experience worry and concern for their sibling and require information and awareness about the condition. Additionally, communication between family members is an important factor in the development of coping skills and understanding. The findings further indicate that parents' perceptions of their healthy child's experiences were in agreement with those of their child. Limitations of the study and implications for parents and professionals are discussed. Directions for future research are presented.

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Acknowledgments

This research would not have been possible without the six families who participated. I thank them for welcoming me into their homes and for sharing their stories. I admire their dedication and strength.

I also wish to acknowledge my supervisor, Dr. Jillian Roberts, for her support and expertise. I express sincere gratitude for her assistance and guidance over the past two years.

I would also like to thank Lani for her friendship and for giving up her time to provide me with endless encouragement, assistance, and enthusiastic support.

I express appreciation and gratitude to Murray. This thesis would not have been possible without the phenomenological weekend mornings, the large coffees, and the sharing of much frustration and confusion as we attempted to make sense of phenomenology and thematic analysis. Thank you for your support and humour.

Finally, I thank Dean, for blessing my days with laughter.

Dedication

I dedicate this to my family. To my parents, for instilling in me a love of learning and for providing me with endless support, encouragement, and financial donations. To my siblings, Lisa, Julie, Sarah, and Mark, who keep me grounded and who show me the value and the importance of sibling relationships everyday.

I also dedicate this to Margot, my first-year friend and companion in catatonia. We have conquered so much together. I could not have done this without you. All the non-fat, sugar-free vanilla lattes in the world could not express how grateful I am for your existence in my life. Thank you for the laughter, the comfort, and the friendship.

Chapter One-Introduction

Research on children has examined the various disorders, behaviours, and illnesses that affect the lives of many children and their families. Findings suggest that although children are fairly resilient, not all are free from developing a chronic illness.

According to Wishnietsky and Wishnietsky (1996), a chronic illness may develop slowly and will often last a lifetime. A chronic illness may be a result of an immune system deficiency or an organ failure. Wishnietsky and Wishnietsky (1996) indicate that although many chronic illnesses are rarely curable, they can be regulated through diet, exercise, medication, and exposure to appropriate resources.

The effects of an illness change over time and vary as a result of the severity of the illness. Chronic illness may cause an absence from school, which could lead to feelings of loneliness and feeling different from others (American Academy of Child and Adolescent Psychiatry, 1999). According to Brown (1993), specific learning disabilities and socialization problems may affect these children's quality of life. Unable to establish peer relationships, an afflicted child may develop low self-esteem. However, a chronic illness does not affect the child alone.

“Life is forever changed for a family when they have a child diagnosed with a chronic illness” (STAR Center, 2002, p. 1). Parents and family members are often the ones who manage and cope with the child's illness. The uncertainty and fears regarding the illness can be a source of great stress for a family, including the siblings, who can often feel neglected (National Research Center for Respite and Crisis Care Services, 2002). According to Anderson and Valentine (1998), illness has

a significant impact on the family system. Uncertainty, health-related changes, financial burdens, and role changes are significant sources of stress for the affected family. Recent work has examined how families and family members manage a chronic illness. Understanding the various ways in which families respond to a chronic illness can help professionals develop interventions and promote optimum adaptation (Wong, 1999).

Knafl, Breitmayer, Gallo and Zoeller (1996) identified the unique styles of family responses to childhood chronic illness. The authors indicate that over 90 percent of chronically ill children will live to at least young adulthood and the family is known to play a vital role in the child's adjustment to the illness (Knafl et al., 1996). According to the STAR Center (2002) everyone in the family is affected by the condition. "Parents may lose days from work, experience financial strain, and be challenged both emotionally and physically as they cope with the care of the child. Siblings are affected, as can be extended family members" (Wong, 1999, p. 1001).

Recent research, however, has just begun to examine the specific effects a child's chronic illness has on siblings. So far, the extant literature has been inconclusive in addressing the exact experiences of siblings. Stoneman and Brody (1993) explain that:

Research on families of children with disabilities or chronic illness has focused primarily on the mother-child dyad. Researchers have often ignored the fact that most children, including those with mental retardation, disabilities, or chronic illness live in families in which other children are also present (p.3).

Additionally, “theory and research concerning chronic medical illness in children focus predominantly on the stresses and adaptations of the patient and parents; the adjustment of siblings has been largely overlooked” (Tritt & Esses, 1988, p. 211). Furthermore, very little research has been collected from the siblings themselves (Horwitz & Kazak, 1990).

According to the National Resource Center for Respite and Crisis Care Services (NRCRCCS, 2002), researchers are beginning to understand that the experiences and the concerns of healthy siblings of children with chronic illness are similar to those of their parents. As with their parents, these children require information about their sibling’s illness. Unlike the parents, however, they have far “fewer opportunities of obtaining this information as most information is not developed for young readers” (NCRCCS, 2002, p. 1). In addition, these children enjoy significantly “fewer programs, services and considerations” (NCRCCS, 2002, p. 1). Janus and Goldberg (1995) further indicate that the quality of the relationship between a child with chronic illness and his or her healthy sibling has rarely been explored. Given the significance of sibling relationships, it is crucial for researchers to pay more attention to this special area.

Statement of the Problem

In response to the gaps in the extant literature, the purpose of this investigation was to answer the following question: What are the experiences of healthy siblings of children with a chronic illness? Given the vast array of chronic paediatric conditions and the scope of the current study, it is impossible to answer this question within the context of every specific chronic illness. Therefore, for this

particular study, only siblings of children with congenital heart disease were investigated.

Purpose of the Study

Given the inconclusiveness of the research, it is necessary to develop a thorough understanding of how a healthy sibling is affected by their brother or sister's chronic condition. Developing a more comprehensive understanding of these children's experiences will advance our knowledge of how affected families cope and function, thereby facilitating the work of professionals who are working to improve the quality of life of these families. Specifically, the purpose of this study was to contribute to the body of knowledge in this area by:

- Gaining a better understanding of how a child's congenital heart disease affects siblings;
- Identifying the daily stressors and challenges these siblings face; and,
- Identifying the experience of the siblings from the perspective of the parents.

Delimitations

As with any study, there are methodological restrictions that influence the design, and therefore, the outcomes of the investigation. It is crucial that these delimitations are acknowledged in advance and in an explicit manner so that the consumers of the research have a framework in which to understand and appreciate the results. For the current study, the following delimitations were imposed by the researcher:

- 1) The study was limited to six school age children.

- 2) The study was limited only to participants who are the siblings of a child with congenital heart disease and who live on Vancouver Island, British Columbia.
- 3) The study was limited to data collected from December 2002 to January 2003.
- 4) Siblings and parent(s) were interviewed together to create a focus group-like atmosphere. Although parents and siblings did have the choice to be interviewed separately, they chose to be interviewed together. Such an approach does have limitations, however, as children may disclose more information during an individual interview.
- 5) All variables, conditions, or populations not so specified in this study were beyond the scope of this investigation.

Definition of Terms

Given that many specialized terms will be used in this study, it is important at this point to offer the working definitions of the following terms in order to ensure proper interpretation of the terminology.

Chronic Illness: “an illness that can last for an extended period, at least 3 months, often for life, and cannot be cured” (Midence, 1994, p. 311).

Congenital Heart Disease: “a structural or functional heart disease that is present at birth, even if it is discovered much later” (Hoffman, 1990, p.25).

Sibling Relationship: Two or more children that “usually share a common [biological] background as well as their parent’s time, interest and love” (McKeever, 1983, p. 209).

Summary

Chapter one presented introductory information regarding the need for future research to address the experiences of siblings of chronically ill children in order to promote awareness about family functioning, coping mechanisms and quality of life for affected siblings. In addition, pertinent definitions of terms used throughout the thesis were provided.

Following this section, chapter two will provide a review of the literature which examines chronic illness within the framework of congenital heart disease. The experience of family members, with special attention to siblings, is examined.

Chapter Two-Literature Review

Introduction

This chapter will provide a review of chronic illness and the effects on families, specifically on the siblings, who in many cases have been overlooked. Information regarding previous studies and research in this area are discussed. As such, this chapter will be organized under the following sections: Chronic Illness; Effects on the Family; Effects on the Parents; Effects on the Siblings; and The Need for Future Research.

Review of the Literature

Chronic Illness

According to Perez (1997), between 10 and 20 percent of all children suffer from a chronic illness. “The management of chronic illness depends to a great extent on pain control (e.g., sickle cell disease) or the reduction of attacks (e.g., asthma), bleeding episodes (e.g., hemophilia), or seizures (e.g., epilepsy)” (Midence, 1994, p. 311).

Differing from an acute illness, a chronic illness may develop slowly and will often last a lifetime. The cause may be due to an immune system deficiency or an organ failure. Although a chronic illness is rarely cured, diet, medication, and adequate exposure to education and resources may influence and help to control the illness and its effects (Wishnietsky & Wishnietsky, 1996).

The most common childhood illnesses include asthma, kidney disease, sickle cell disease and congenital heart disease. According to Hoffman (1990), “congenital heart disease occurs in approximately 1 per cent of liveborn children, but in a much

higher percentage of those aborted spontaneously or stillborn” (p. 39). Congenital heart defects are one of the most serious and pervasive chronic illness in children (Davis et al., 1995). Other illnesses such as childhood cancer and diabetes are not as common, but frequently occur in children today.

Infectious diseases that once claimed the lives of many children throughout history have been eliminated due to medical advances, proper sanitary practices, and vaccines (Newacheck & Taylor, 1992). Some illnesses such as polio and tuberculosis have declined considerably over the past fifty years. “However, reductions in the prevalence of childhood chronic illness have not been nearly as dramatic” (Newacheck & Taylor, p. 364). With the advances in medical knowledge and treatments, many chronically ill children (who typically would have died), are now surviving into adulthood (Newacheck, & Taylor, 1992). “These changes have affected the types of care that families provide, and often the meaning of the illness for the child and family” (Kazak & Nachman, 1991, p. 2). These gains have led researchers to study the effects chronic illness have on the family system. Although “conducting family research is a challenging and relatively new field for psychologists” (Kazak & Nachman, 1991, p. 3), research does suggest that families are seriously affected by a child’s illness.

Effects on Families

Research has addressed the importance and significance of relationships at various stages of the lifespan. It is understood that parent-child interactions change with the child’s maturation and developmental stage. In early childhood, parents provide the context for learning and conceptual development. Throughout the later

years, parents instill self-control in children, thereby facilitating their pursuit of independence (Lamb, Hwang, Ketterlinus & Fracasso, 1999).

Family relationships provide the context for growth, development and support. According to Germain (1991), a family is considered to have many functions. Some of these include raising children, socializing all individuals into gender-specific roles that are viewed as being acceptable by society, and household maintenance such as domestic labour, authority and decision making. Germain (1991) additionally suggests that a family functions as a unit to produce effective, developed members who will make positive contributions to society throughout the course of life.

A child's chronic illness is known to have a serious impact on the family. "The care of a child with a severe and chronic physical disorder makes considerable emotional and practical demands on all family members" (Taylor, Fuggle, & Charman, 2001, p. 953). The STAR Center (2002) suggests that life is forever changed when a family has a child diagnosed with a chronic illness. Everyone in the family is affected by the condition. Wong (1999) indicates that parents experience both emotional and physical challenges when caring for a child with a chronic illness.

Effects on Parents

According to the Nemours Foundation (2002), taking care of a chronically ill child may be one of the most draining and difficult tasks parents can face. "Parents of chronically ill children face a demanding and often lonely ordeal" (Gordon, Hsia & Kwok, 1996, p. 59). Gordon and her colleagues (1996) suggest that parents of ill children may also become over-whelmed with the challenges of raising a child who is

ill. Parents are faced with the worries regarding the effects of the illness and have to accept the fact that their child is not going to have a typical childhood. They are required to assume numerous tasks and responsibilities in caring for their child, often before they have had a chance to mourn or grieve the loss of a normal child (Gordon et al., 1996). As a child with a chronic illness begins school, additional stressors arise. Parents are required to give control of the caregiving to teachers and other school personnel, when in many cases the school has limited knowledge and expertise on how to care for the student. If the child is physically disfigured, that too, would create anxiety in the child as well as the parents. Caregiving can be a huge burden on parents as they are expected to know a great deal about their child's illness. They are expected to make decisions and educated judgments on the need for treatment and may feel enormous guilt if they make a mistake or misjudge their child's symptoms (Gordon et al., 1996). Additionally, parents may believe that they have limited social support if they feel that no one understands what they must be going through. Parents are also faced with the financial constraints that a chronic illness creates. Maintaining health insurance, daily home care, hospitalization, and treatment are aspects of a chronic illness that can create enormous financial stress (Gordon et al., 1996). It is therefore clear, that caring for a chronically ill child can take its toll on parents in a number of ways.

According to Streisand, Braniecki, Tercyak and Kazak (2001) "parents caring for children with physical limitations are at risk to experience poor mental health outcomes" (p. 156). Stress also affects an individual's ability to remember, process information and learn. When parents are under a great deal of stress, they are prone to

an inability to adequately comprehend a child's treatment and condition. A parents' level of stress may also create elevated levels of stress in the child (Streisand et al., 2001). Streisand and her colleagues (2001) suggest that a parent's response to medical procedures, communication with family members and doctors or their role as a caregiver may also have a substantial effect on their mood and emotional well-being.

Parents of repeatedly hospitalized children are under a great deal of stress and have a high potential for long lasting problems. According to Burke, Harrison, Kauffman and Wong (2001), hospitalizations may put chronically ill children at a greater risk of psychiatric and social problems compared to their healthy counterparts. Burke and her colleagues suggest that a parent's distress and reaction to hospitalizations may consequently affect their ability to cope with their child's illness, as well as the child's ability to accept and react to their illness. Burke et al. (2001) suggest that professionals must find strategies that will assist parents to work with their child throughout hospitalizations. The amount of stress on parents who care for a chronically ill child varies among families. It can, however, also be expressed as a function of gender.

In a study by Knafl and Zoeller (2000), the authors reported the outcomes of a secondary analysis of a larger study which examined the experiences of families of chronically ill children. In the original study, the authors looked at the impact a chronic illness had on family life. "For the secondary analysis, the unit of analysis shifted from the family to mother-father pairs to determine the extent to which parents in the same family held shared or discrepant views of their situation" (Knafl

& Zoeller, 2000, p. 291). Data for the study were obtained from 43 couples and seven wives whose husbands chose not to participate. Using purposive sampling techniques, the authors selected a sample of families in which a child between the ages of seven and 14 years had a chronic illness that required daily monitoring and management. A variety of chronic illnesses including asthma, diabetes, and rheumatoid arthritis were the most common illnesses that affected the children.

Parents were involved in individual qualitative interviews that addressed the impact of the illness, including how it was defined and managed. In addition, the parents completed the *Feetham Family Functioning Survey* and the *Profile of Mood States*. The findings of the study suggest that most fathers and mothers develop a shared view of their child's illness. In most cases, this view minimizes the impact on family life. However, some parents reported very individual experiences of their child's illness. The authors indicate that because parental differences may contribute to child and family functioning, more work in helping parents adapt to the illness is required. In addition, the authors concluded that nurses and other professionals must provide appropriate assessments and interventions based on how each individual manages the child's illness.

Wong (1999) describes similar gender differences. According to Wong (1999), fathers of children with special needs struggle with issues that are quite different from those faced by mothers. Wong (1999) further indicates that historically, men were not expected to share their feelings. This may still be the case for some men today. Thus, they are often left without the emotional support required to help them cope. The father's self-esteem may also be compromised as he may feel

unable to protect the family or manage the increasing financial burdens (Wong, 1999).

It is clear then, that the needs of both parents must be addressed in order to promote adequate family functioning. However, it is also important to acknowledge the effects and experiences that a child with a chronic illness has on not only the parents, but also on other family members such as the siblings.

Effects on Siblings

According to Labato, Faust, and Spirito (1988), the relationship between siblings may be an important precursor to relationships throughout life. Stoneman and Brody (1993) further indicate that “as children play together, they learn important social and communication skills” (p. 5). It is evident then, that “in a very real sense, children encounter most of the significant social experiences to be faced as they progress through life in the microcosm of sibling relationships” (McKeever, 1983, p. 210).

Stoneman and Brody (1993) indicate that little is known about the factors that influence the relationship between individuals with a chronic illness and their healthy brothers and sisters. Kazak and Nachman (1991) suggest that “concerns about the effects of illness on siblings are frequently raised by parents, yet siblings are rarely included in systematic research” (p.4). Additionally, the experiences of healthy siblings have not been thoroughly investigated as most family research has focused on the mother-child dyad (McKeever, 1983). Further, in many investigations, siblings have rarely spoken for themselves as descriptions have been based on parental observations and interpretations (McKeever, 1983).

Sibling relationships are vital to the socialization and education of each individual. They provide the context for sharing and negotiations as well as for emotional experience and development (Lebato et al., 1988). Given the significant influence siblings have on each other, it would appear that the illness of one would certainly affect his or her healthy siblings to some degree (McKeever, 1983).

The NRCRCCS (2002) suggests that the concerns of individuals with a chronically ill sibling include feelings of loss and isolation as much of the parent's time and attention is consumed by the disability or illness. Healthy siblings often have less knowledge about the illness and ways they can help, as resources and information are not usually created for young readers. Having a chronically ill brother or sister may leave the healthy siblings feeling concerned, worried and angry (NRCRCCS, 2002). Children may fear they have their sibling's illness or may catch it, which creates anxiety and stress in an already stressful situation. Berkobien (2002) also indicates that children may begin to feel guilty that they do not have the disability or that they are to blame for their sibling's condition. If the sibling is physically affected by an illness, the children without the condition may feel embarrassed and may refuse to invite friends over or be seen with their sibling (Berkobien, 2002). According to Berkobien (2002), when parents are consumed with their child's illness, siblings may react with jealousy and anger, often resulting in resentment towards the brother or sister. Tritt and Esses (1988) further indicate that such resentment towards a sibling may be a result of the healthy child's worry and "their sense of exclusion and loss" (p. 217). Healthy children may also feel the pressure to excel in sports or school in order to make up for the chronically ill sibling's inability to do so (Berkobien, 2002).

However, according to Wong (1999), many studies to date have shown inconsistent findings regarding the experiences of siblings. Some confirm that siblings are at higher risk for maladjustment; others report no significant differences between siblings of chronically ill children and siblings of healthy children; and still, others illustrate beneficial aspects of having an ill sibling.

Breslau et al. (1981) examined the psychological adjustment of normal siblings of children who were disabled. The majority of the children used in the study were inflicted with a variety of illnesses including cystic fibrosis, cerebral palsy, myelodysplasia, and various other multiple handicaps that required the child to receive clinical care. The sample consisted of 239 families in which the normal siblings were between the ages of six to 18 years. The siblings' psychological functioning was measured using the *Psychiatric Screening Inventory* which assesses psychiatric impairment in children. Impairment in this inventory was defined according to how well a child functions in a context with parents, teachers, siblings and peers. The *Psychiatric Screening Inventory* "was constructed by a factor analytic method using a large pool of descriptive items covering extensively the domain of child behaviour" (Breslau, 1981, p. 346). The premise behind their research is that normal siblings tend to be neglected because the majority of parental attention and care is given to the sick child. This can have everlasting effects on the emotional well-being of the healthy siblings. These children may act out, feel jealous and angry and may at times, assume roles and responsibilities like those of the parents, in order to help care for the child. The findings of this investigation indicate that the siblings of chronically ill children did not manifest higher rates of psychological impairment when compared to control

subjects. These children did, however, score higher on scales measuring interpersonal aggression with peers and within the school. The gender and birth order of the healthy child did appear to be related to psychological functioning. Male siblings that were younger than the ill child were psychologically worse off than their female counterparts. The authors concluded that overall, siblings were not worse off than those in their control groups. They did suggest, however, that future investigations examine other factors apart from parental attention that may contribute to higher levels of aggression in healthy siblings of chronically ill children.

A positive self-concept in healthy siblings appears to affect the self-concept in the child with a learning disability. When a child has an illness or disability, there may be a general sense of empathy for the child by a healthy sibling. This can have a positive effect on the unhealthy brother or sister. For example, Janus and Goldberg (1995) investigated the relationship of healthy siblings' empathy to the psychosocial adjustment of children with a congenital heart disease (CHD).

Janus and Goldberg (1995) suggested that siblings with a chronically ill brother or sister are more capable of empathy, sensitivity, and an awareness of other's suffering. Prior to the study, the authors anticipated that children with CHD would have fewer behaviour problems if their siblings had higher empathy than if their siblings had lower empathy. They also suggested that sibling empathy is positively related to sibling behaviour towards the child with CHD.

The participants in Janus and Goldberg's study consisted of 28 sibling pairs, between the ages of 3.5 and 11 years, in which one child had CHD. Mothers were interviewed by phone and completed the *Child Behaviour Checklist (CBCL)* for both

children. Each child completed one empathy task and along with the mother, rated the healthy sibling's behaviour using the *Sibling Inventory of Behaviour*. Two empathy tasks were chosen due to the age range of the subjects. The *Bryant Empathy Task* was chosen for siblings above five years of age and a modified procedure based on Borke and Lewis was used for siblings under five years of age.

The findings of the study indicate that sibling's empathy was not related to behaviour problems of chronically ill children. The study does, however, illustrate that siblings who express higher degrees of empathy toward their ill brother or sister are perceived as more positive in their interactions toward their ill sibling. In addition, "maternal perceptions of siblings' behaviour, though consistent with other maternal ratings (*CBCL*), were not highly concordant with the ratings by the child with the illness, and generally not related to the siblings' empathy. However, mothers judged siblings in the high empathy group to be more resentful of the child with CHD" (Janus & Goldberg, 1995, p. 328). Although the study did not illustrate that the healthy sibling's behaviour was a mediating factor for the chronically ill child's maladjustment, the study does indicate a connection between a child's empathetic abilities and the chronically ill sibling's perception of the healthy child's behaviour toward him or her (Janus & Goldberg, 1995).

Dyson (1996) further examined this phenomenon in a study that addressed the self-concept of siblings in families where one child had a learning disability. The sample in this investigation consisted of 19 families in which there was one child with a learning disability and one child without, both between the ages of 7 and 14 years. Sixteen questionnaires were completed by the mother, one was completed by the

father, and two were completed by both parents. In order to meet the criteria of the study one sibling in each family must have been diagnosed as having severe learning difficulties. The comparison sample was drawn from previous work by the Dyson and consisted of 55 normally achieving children.

Using the *Questionnaire on Resources and Stress-Short Form*, the *Family Environment Scale-Form R*, and the *Piers-Harris Children's Self-Concept Scale: The Way I feel About Myself*, the author examined parental stress, family functioning and sibling self-concept. The SPSS-X computer software program was used to analyze the quantitative data. The data were then analyzed using the constant comparison method.

The findings of this study illustrated that almost half of the families indicated having no problems with the siblings at home. More families, however, suggested problems for the family, and even more reported problems with the school. Relationships between siblings were generally positive and most parents reported the non-disabled sibling to be understanding and patient with the sibling with the disability. A significant problem reported by the parents, however, was feelings of guilt due to having to spend so much more time with the child with the disability than with their other children. In addition, Dyson (1996) indicates that the self-concept of the non-disabled siblings may be related to their sibling with a disability. Although the study calls for further investigation of siblings of children with disabilities, it does illustrate the fact that a child's perception of other's attitudes may be a significant contributing factor towards their self-concept and that families of children with learning disabilities do have needs that must be supported (Dyson, 1996).

It is clear, therefore, that when helping a family cope and adjust to a child's chronic illness, siblings must be included and their needs must be addressed as they are part of the family unit. "Variables such as the nature and the extent of the illness, the age and the gender of the sibling, and the resources available to the family all play a role in shaping the healthy sibling's response to the situation" (Gordon et al., 1996, p. 62). Health professionals play a part in accommodating the needs of all family members. Information regarding the needs of siblings will aid in the provision of adequate material and care for these individuals.

The extant literature does indicate that brothers and sisters of children with chronic illness are, at least to some degree, affected by their sibling's condition. Continued research in this area is required in order to develop a more comprehensive knowledge base regarding the experiences of healthy siblings. These children need to be considered and have their needs identified and met in order to promote better quality of life, optimum development and adequate adjustment to the effects of their brother or sister's heart disease. McKeever (1983) further states:

The fact that many siblings of chronically ill children do not develop symptoms that dictate professional intervention may reflect their capacity to function under stress. This does not, however, absolve health professionals from their clear responsibility to include siblings in both their practice and research endeavours (p. 217).

The Need for Future Research

According to Kazak and Nachman (1991), "conducting good family research is difficult, and many of the theoretical and methodological issues involved are

exceedingly complex” (p. 11). Despite the challenges, family research has made considerable gains over the years. Siblings, however, have remained an overlooked population in family investigations. Very little research has addressed the needs of siblings as they have had little opportunity to speak for themselves (McKeever, 1983). Given the lack of conclusive research, it is strongly suggested that siblings of chronically ill children are a population at risk and must be considered in future research (McKeever, 1983). Information is required about the daily stressors and challenges these healthy children face and the effects their chronically ill siblings have on their development. In addition, it is vital for health professionals to hear from the healthy siblings themselves, in order to implement programs that address the needs of these children and their families (McKeever, 1983).

Summary

Chapter two has provided an examination of the selected literature on chronic illness and family adaptation. This literature examines the need to further understand the experiences of families of chronically ill children with specific attention to the healthy siblings. Although findings of extant literature have been inconclusive, studies do suggest that a child’s chronic illness affects the psychological development of siblings. It is hoped that with continued research, we will extend our understanding of the effects chronic illness has on healthy siblings in order to promote the quality of life of these individuals.

Chapter three will discuss the methodology to be employed in this study. A qualitative paradigm using a phenomenological approach will be described.

Chapter Three-Methodology

Introduction

Chapter three outlines the methodology chosen for the study which explores the research question: What are the experiences of healthy siblings of children with congenital heart disease? This chapter will provide a description of the research paradigm employed in this investigation to answer this question and the rationale for its use. Information regarding the research design, procedures, participants, instrumentation, data collection, and data analysis will also be presented.

General Approach/Paradigm

Since the objective of the study was to develop an in-depth understanding of the experiences of individuals within a family context, a qualitative model has been used. “Qualitative research is a form of inquiry that explores natural phenomena in the natural settings and uses multi-methods to interpret, understand, explain and bring meaning to them” (Anderson, 1998, p. 119). The intention of qualitative research is not to generalize, “but to uncover the implicit meaning in a particular situation from one or more perspectives” (Anderson, 1998, p. 90). Unlike quantitative research, a qualitative investigation uses the natural setting as the direct source of information and the researcher as the key data collector (Evans, 1998). Furthermore, “a fundamental assumption of the qualitative research paradigm is that a profound understanding of the world can be gained through conversation and observation in natural settings rather than through experimental manipulation under artificial conditions” (Anderson, 1998, p. 119). In addition, qualitative researchers focus on

meanings of experiences rather than solely on behaviour, as they attempt to study the world from the perspective of the individual being studied.

Creswell (1998) further describes qualitative research as:

An inquiry process of understanding based on distinct methodological traditions of inquiry that explore a social or human problem. The researcher builds a complex, holistic picture, analyzes words, reports detailed views of informants, and conducts the study in a natural setting (p. 15).

Entering Assumptions

The qualitative orientation encourages the researcher to approach the data without preconceived notions or hypotheses. If the researcher does have entering assumptions, however, it crucial to bracket (or suspend) these beliefs in order to prevent biases and presuppositions in qualitative investigations. “In order to understand a given phenomenon, one attempts to suspend or to put in abeyance one’s preconceptions and presuppositions” (Colaizzi, 1978, p. 12). This process of bracketing encourages the researcher to undertake an investigation that is free of their own beliefs, knowledge and prior experience as a way of achieving openness and naiveté in the investigative process (Moustakas, 1994). Ramsland (2002) further explains that a researcher brackets or suspends one’s beliefs by listening openly to other’s stories and experiences. It was the researcher’s intention to bracket her own personal beliefs, to reflect upon these beliefs, and to state them explicitly at the onset of research. The researcher carefully considered her entering assumptions and they are as follows:

- 1) The participants would be honest with responses;
- 2) The participants would accurately carry out the instructions provided by the researcher;
- 3) It is my belief that the needs of all individuals within a family context need to be addressed in order to promote better quality of life;
- 4) Based on my review of the literature, I believe that healthy siblings have been seriously overlooked and require more attention;
- 5) The review of literature also encouraged me to believe that while some healthy siblings adapt well to a brother or sister's chronic illness, others may feel jealous, neglected, scared, and lonely. I was prepared to approach these issues with an open mind and to provide a thorough examination of the lived experiences of healthy children of siblings with congenital heart disease.

Research Design

In order to develop a comprehensive understanding of the lived experiences of siblings, phenomenological methods were employed. The purpose of phenomenology is to collect naïve descriptions of the experience under investigation (Valle & Halling, 1989). These descriptions can provide specific statements or instances from which the researcher can tease out themes and structures of that experience. Therefore, “phenomenology is aimed at understanding the meaning of experiences in our everyday lives” (Anderson, 1998, p. 121). In a phenomenological interview, the participants are asked to explain what the experience is like for them in order for the researcher to better understand the meaning of that experience. Moustakas (1994) indicates that:

The phenomenological interview involves an informal, interactive process and utilizes open-ended comments and questions. Although the primary researcher may in advance develop a series of questions aimed at evoking a comprehensive account of the phenomenon, these are varied, altered, or not used at all when the co-researcher shares the full story of his or her experience ... (p. 114).

In other words, a phenomenological approach involves a dialogic conversation between the investigator and participant whereby the researcher poses questions to the participant that allow for full disclosure of the phenomenon under investigation. Using such an approach is intended to enable the researcher to understand the lived experience of an individual thereby identifying the individual's perception in a given situation or context (Valle & Halling, 1989; Lester, 2000). The phenomenology tradition involves understanding this experience "in order to obtain comprehensive descriptions that provide the basis for a reflective structural analysis that portrays the essences of the experience" (Moustakas, 1994, p. 13). The aim is to determine what an experience means for an individual who has lived that experience and is able to provide a comprehensive description of it. From such descriptions, thematic meanings are derived. By employing this approach, the researcher was better able to understand the experiences of siblings of chronically ill children. Parents were included in the interviews so as to further the understanding through multiple perspectives about the experiences.

The use of multi-perspectives is "referred to as triangulation, whereby various sources of data point in the same direction relative to a given conclusion" (Anderson,

1998, p. 148). It was expected that in this “multiple-participant research, the strength of inference which is made increases rapidly once factors start to recur with more than one participant” (Lester, 2002, p. 2). In addition, “validity is much improved through the use of multiple sources of data for each question. With proper triangulation, it will be difficult to refute conclusions which follow logically from multiple data sources” (Anderson, 1998, p. 150).

By employing such an approach, the results have led to a deeper understanding of the lived experiences of siblings of children with congenital heart disease. The knowledge gained can be used to further develop practical theory or to challenge action.

Participants

Participants were purposefully selected to provide a variety of experiences and consisted of both parents and healthy siblings. These participants were chosen from a larger cohort of subjects participating in a study organized by the supervisor of the researcher’s committee. Specifically, the sample included six Caucasian siblings of both genders (between the ages of 7 and 15) and their parent(s). This number of participants is typical of phenomenological research and is considered to be adequate and to represent a reasonably sized sample (Creswell, 1998). Out of the six participants, two were female and four were male. Additionally, three of the participants were older than their sibling with congenital heart disease and three were younger. All of the participants were selected from families who have a school age child with congenital heart disease who reside on Vancouver Island, British Columbia. Further, one or more parents participated depending on the preference of

specific families. In this investigation, two families had both the mother and father participate in the interviews (total $n = 14$). Neither of the fathers, however, remained present throughout the entire interview. An overview of the participants is presented in Table 1.

Table 1
Overview of participants

Participant Demographics	<u>Families</u>					
	1	2	3	4	5	6
Age of healthy sibling	15	8	12	9	15	7
Gender	female	male	male	male	female	male
Older/younger than ill sibling	older	younger	older	younger	older	younger
Parents present	mom	mom	mom/ dad	mom	mom/ dad	mom
Total family members present	2	2	3	2	3	2

Data Collection

An interview format that allows for open-ended comments was used in order to develop a comprehensive understanding of these families' experiences (Roberts & Cairns, 1999). Each interview was conducted at the participant's home and lasted approximately one to two hours. Prior to administering the interviews, the researcher observed four phenomenological interviews conducted by her supervisor and her supervisor's research assistant. This was done to ensure proper administration and analysis of the researcher's own interviews.

In interviewing the siblings and parents, the researcher posed questions to elicit information on their daily experiences and quality of life (see Appendices C and D for both interview guides). The interview process began with: “What is it like to have a brother or sister with congenital heart disease?” This was followed up with prompts based on Tritt’s (1983) interview guide. Prompts were required in order to obtain a comprehensive description of the experiences and to ensure a free flow of ideas. Each interview followed the same format. The researcher rephrased the questions with the parent(s) or guardian(s) of these children in order to obtain their *perceptions* of the experiences of their healthy child. The first interview was conducted to obtain preliminary data. The researcher then transcribed and thematically analyzed the data. The second interview was conducted in order to ensure the accuracy of the typed transcript and the thematic representation of the lived experiences.

The interview prompts were based on Tritt’s (1983) measure on “siblings’ thoughts and feelings about the impact of chronic illness on them and their families” (Tritt & Esses, 1988, p. 214). Using the measure as a guide, the interview covered such areas as: the healthy siblings’ knowledge of the illness; perceptions of the impact on family members, including the ill child; the daily experiences of the healthy child; and the negative consequences and positive impacts of having an ill brother or sister (Tritt & Esses, 1988). The final portion of each interview was allocated to asking for parent and child recommendations or advice for other families where a child has congenital heart disease.

The siblings and parents of each family were interviewed together to create a focus group-like atmosphere and family-centered approach. However, parents and siblings had the choice of being interviewed separately if they preferred and this choice was outlined to the families in advance of the first meeting. All families in the present study, however, chose to be interviewed together

There are strengths and weaknesses of both interview formats. Strengths of the focus group-like approach include synergy of discussion whereby the interactions between the members enhance the discussion and provide for a more thorough description of the experience than an individual approach would. It also facilitates the scheduling of interviews in that the families will have to provide time to be interviewed on only one occasion. This format does, however, have some limitations as the siblings and parents may feel uncomfortable sharing information around other people. Using an individual interview approach enables the participants to disclose information that they may not have chosen to share with the inclusion of other family members.

Procedure for Data Analysis

Once the recorded interview process was complete, the interviews were thoroughly examined for themes and patterns of experience following a protocol analysis procedure developed by Colaizzi (1978) and modified in the work of Roberts and Cairns (1999). The first elements of this procedure included:

- 1) gathering a sense of each transcripts' meaning through repeatedly listening to the interview tapes;
- 2) extracting significant statements from each paragraph; and,

- 3) formulating statements of meaning and/or themes from these extracted statements (Roberts & Cairns, 1999, p.36).

As mentioned above, the transcripts were then sent back to the participating families to ensure accuracy and validation of the thematic representation of the experiences (see Appendix F for confirmation letter). Once each participant had a chance to look over their transcriptions, a second interview was conducted by phone. Three of the participating families suggested minor changes during the second interview. These suggestions were noted and completed by the researcher. Once the transcripts were deemed accurate by the participants, the researcher formulated clusters of themes based on their central meaning.

In the present study, a theme was included if it was common to at least one half of the participants interviewed. The exact percentage of participant representation is offered in the thematic tables in chapter four. The clusters of themes were then labelled according to their most central meaning. These clusters were finally sorted into categories which were separated and labelled according to their central meaning. The categories were labelled as follows: Family, Social Development, and Well-Being. The major categories and thematic structure were then “integrated into an exhaustive description of the investigated topic” (Colaizzi, 1978, p. 61). (See Appendix B for a visual representation of the data analysis procedure).

Ethical Considerations

Prior to conducting the interviews, ethical approval was obtained from the University of Victoria (see Appendix A). Interviews were conducted with participants who had provided consent for themselves as well as from their parents (see Appendix

D and E). Participation was voluntary and withdrawal from the study at any time was permitted.

The interviews took place at the participants' location of choice. All families chose to be interviewed in their homes. Participants were updated periodically regarding the progress of the study.

Participants and guardians were informed that their anonymity would be ensured as participant's data were kept anonymous throughout the analysis and investigation. No names have been attached to the data; identity of the participants was not revealed. All records will be contained in a locked cabinet throughout the duration of the study. Taped interviews will be burned after five years.

Summary

A qualitative paradigm using a phenomenological approach was used to investigate the following research question: What are the experiences of healthy siblings of children with congenital heart disease? Chapter three provided a thorough description of the chosen methods and the rationale for their use. Phenomenological methodology will deepen the understanding of the experiences of siblings of chronically ill children.

Chapter four will provide a description of the results of the data analysis derived from each interview. The essential structure of experience is outlined as well as the major categories and thematic structure.

Chapter Four – Results

Introduction

Chapter four provides an introduction to the participants as well as an overview of the results from the data analysis. As such, the chapter is organized into four parts. The first section provides a brief background of the participants.

The second section outlines the essential structure of the experience investigated and will present the primary thematic categories derived from the data which is further illustrated in Table 2.

The third section of the chapter explores the categories and thematic structure. Table 3 illustrates the clusters and themes that are derived from each category. Additionally, quotations from the participants will be included to convey the meaning of the lived experience.

In the fourth section of the chapter, parent and child recommendations are presented. These recommendations refer to the suggestions healthy siblings and parents offer to other families where a child has congenital heart disease.

Brief Profile of Participants

The following names have all been changed to protect the identity of the participants.

Karen is a 15-year-old female. She is one of two children in her family and is older than her sibling with congenital heart disease.

Joey is an eight-year-old male. He is the second of three children and is younger than his sibling with congenital heart disease.

Owen is a 12-year-old male. He is one of two children and is older than his sibling with congenital heart disease.

Ben is a nine-year-old male who is one of two children. He is younger than his sibling with congenital heart disease.

Marie is a 15-year-old female and is one of three children. She is older than her sibling with congenital heart disease.

Aaron is a 7-year-old male. He is one of two children and is younger than his sibling with congenital heart disease.

Essential Structure of Experience

This investigation centered around six school age children, all of whom had a brother or sister with congenital heart disease. The goal of this research was to better understand what it is like to have a chronically ill sibling. More specifically, this study addressed what the lived experience is like for these children.

The family-centered interviews enabled the healthy siblings and their parent(s) to share the experience of being in a family with a chronically ill child. They discussed openness about and communication around the sibling's congenital heart disease and the impact it had on the family as a whole. Many of the healthy children were influenced in some way due to their sibling's condition. The children spoke about it being an everyday concern to which they have become accustomed. Some of the children shared how they are always looking out for their sibling and ensuring his or her safety. Although each family's experience has been different, all of the children spoke highly of their sibling, cared greatly about their brother or sister's health and well-being, and felt supported by their family.

In addition to family support, many of these children discussed the social support they received from their peers. All of the children felt satisfied with the number of friends they had. Although not all of their friends knew about their sibling's condition, many of the children indicated that they would feel comfortable sharing that information with their peers if they were asked. Moreover, the parent(s) also felt as though their healthy child had many friends and was socially accepted and satisfied.

As well as social satisfaction, the children described their sense of well-being. These descriptions involved discussing experiences around worry and happiness as well as the benefits of having a sibling with congenital heart disease. The children spoke of visits to the Vancouver Children's Hospital, the need for future surgeries, the physical impact congenital heart disease has on their siblings, as well as the enjoyment they receive from simply having their sibling for a playmate. Despite the ongoing concern they and their parents shared regarding the chronic condition of their sibling, most of the children described feeling content with their lives, felt loved, and coped effectively with their sibling's illness.

As a way to conclude the interviews, the children and parents were asked to offer recommendations or advice to other families where a child has congenital heart disease. Children indicated the importance of asking questions, of getting involved, and of understanding the symptoms and health and wellness of the sibling. Some parents advised children to speak up when they want to be heard and to look out for their sibling. Most importantly, both children and parents advised other families to treat the sibling as a normal child

Categories and Thematic Structure

The analysis of each interview produced three main categories: 1) Family, 2) Social Development, and 3) Well-Being. Each category consists of three theme clusters. Table 2 provides a visual overview of these categories and theme clusters. Tables 3, 4, and 5 illustrate the themes within each cluster. Included in each cell of these tables are the percentages of how many participants formed each theme grouping. In other words, this percentage refers to the number of participants whose statements created each theme. All of the theme groupings contain a representation of at least one half of the participants interviewed.

Table 2
Categories and Clusters

Categories		
Family	Social Development	Well-being
Clusters within each Category		
Impact on Healthy Child	Peer acceptance	Worry
Impact on Family	Peer awareness	Benefits
Impact on Sibling Relationship	Teasing	Awareness

Category 1: Family

The family played a vital role in the lives of these children. As for many of us, it is through our families and the relationships between the family members in which we acquire the social skills and the emotional support needed to enhance our sense of well-being and quality of life. For these children as well, the relationship with their

siblings and parents provided the context for support, comfort, and emotional satisfaction.

Both the children and their parents were able to discuss the impact congenital heart disease had on their daily lives. In addition, the participants spoke of the consequent adaptations and limitations in their daily lives that they had to accommodate. Due to the fact that their sibling's heart condition has been a part of their lives since early on, these children described knowing no other way of life. They have become so accustomed to living along side a sibling with a chronic health condition, that it really is not seen as a burden, but simply a way of life.

The family category contains three main clusters: 1) Impact on Healthy Child, 2) Impact on Family, and 3) Impact on Sibling Relationship. The themes within each cluster that emerged from the data are depicted in Table 3. Each of these themes are further discussed and enhanced with the inclusion of participant quotations. Each cell presents the percentage of participants that created each theme grouping.

Table 3
Family – Themes Within Each Cluster

Clusters		
Impact on Healthy Child	Impact on Family	Impact on Sibling Relationship
Themes within each Cluster		
Parental Perceptions (83%)	Adapting (83%)	Parental Perceptions (83%)
Positive Perceptions (67%)	Perceptions of limitations (83%)	Positive Impact on Relationship (100%)
Negative Perceptions (83%)		Negative Impact on Relationship (83%)
Perception of Equal Treatment (83%)		Impact of Age on Relationship (67%)

Theme Cluster 1: Impact on Healthy Child

The healthy siblings were asked to share their experiences of having a sibling with congenital heart disease. All of the families interviewed described their relationship as close and felt supportive of each other. Furthermore, the siblings in each family were close in age. Therefore, to some degree, these children were affected by their sibling's congenital heart condition both positively as well as negatively. Parents were also included in the discussions in order to better understand their perspective on what it may be like for their healthy child.

Parental perceptions. When asked for their perceptions about how the heart condition may impact their healthy child, most parents were aware of how they were affected and many demonstrated concern about the child feeling left out. Ben's mother spoke of her worry that more attention is given to her sick child: "Sometimes I wonder if he thinks we spend more time and attention on his sibling...because, you

know, she does need more help...with certain things, you know, physical things and sometimes homework things.”

Karen’s mother indicated that she feels as though her healthy child may feel less loved: “Sometimes she thinks I love him more. She does, she would never say it but I think she thinks that.”

During an interview, when Owen described feeling as though more attention is given to the sibling, his father replied that this was not the case as the children were treated differently due to age:

We expect more of you because you’re older. It’s a little different. Is she treated any differently because of her condition? Like she doesn’t get away with more because of what’s wrong with – a heart defect. It’s got nothing to do with a heart defect...

Joey’s mother spoke of how the child’s illness affects the sibling relationship: He tends to be bossy with his (healthy) brother because everything is focusing on him so he (healthy sibling) tends to take a back seat a bit.

In addition to discussing the daily impact congenital heart disease had on their healthy children, many parents spoke of the toll hospitalization took on their healthy child. Many children had to stay with relatives or friends while their sibling was in hospital. This was, in some cases, difficult for the healthy children. Owen’s mother illustrated the impact it had on her son:

Well, it’s the stays at the hospital that affected him in particular. He gets very angry at that – he doesn’t know how to let out that anger most of the time. But, it’s also hard if we have to stay at other people’s homes if she gets

hospitalized for surgeries and stuff. He's really good at staying at other people's homes though, he just walks in, "I'm home."

Owen's father spoke of how boring the hospital was for his son and how staying with friends and families was better for him: "...He didn't care for it. It was boring and a drag."

Parents also spoke of how challenging it was for their healthy child to be able to understand their sibling's illness at such a young age. Marie's mother indicated that her daughter had behaviour problems when young:

Well, when (sick child) was born, I had to stay in Vancouver for probably a month and so she was just totally confused and unhappy and she had a lot of behaviour problems because I was not there for her.

The mother of Owen shared how much of an influence her child's heart condition had on her son when her daughter was first diagnosed:

When he was five, she was born and it made a huge impact. He didn't want to go to school, he didn't want to do anything, he was worried about her life and worried about how he could change her life so nothing serious would happen. And then as the years went on, all he thought about was her getting hurt. So his analogy to that, he would say to me at night was, "when I'm at school I worry that some bad guy's going to come and get her."

The same mother spoke of how Owen didn't fully understand what was going on and how he wanted to fix his sibling's broken heart:

I took him to a psychologist because he was having some issues and she explained it to him that she had a broken heart, that he would not get the

broken heart. He was always worried that he wanted to fix her broken heart – “I want to protect my sister enough that this will, nothing serious will ever happen.”

Despite the toll congenital heart disease had on the healthy children, many parents interviewed spoke of the enormous amount of care and concern their healthy child had for their sibling. Some parents spoke of how supportive the siblings were of each other. Others shared how much their healthy child looked after the sibling and showed concern for the needs of their brother or sister. Owen’s mother further indicated that her child has always looked out for his sibling: “It was like he was meant to be there to protect her, because he has been there to protect her.”

Positive perceptions. The healthy siblings were also very informative when it came to sharing their experiences of a brother or sister with congenital heart disease. Most of these children indicated a closeness to their sibling and spoke of caring deeply about their brother or sister’s health and well-being. Karen explained: “If he’s not feeling well, I’ll just go up and give him a big hug or cuddle with him on the couch...”

An awareness and concern for the needs of the sibling was also evident. Karen indicated that she knew her brother did not want his illness to be a made into a big deal:

He had a coach and we told him he has a heart condition and we told him all about it and we said, but don’t go up to him and say “Oh are you feeling ok? Because if you feel bad, get off right, just take it easy.” And he gets upset

when people do that because it makes him think about it and it makes people think about it.

Understanding the needs of their siblings and helping them to enjoy their lives was very important to the children. Many of the children interviewed spoke of their siblings' strengths and capabilities. Karen further explained that she just wants her brother to enjoy his life: "You don't want him to have to stop playing soccer and stop his activities..."

Although it was important for the child to know that her sibling was able to enjoy his favourite activities, it was also comforting for Karen to realize that although he was living his life to the fullest, he was additionally taking care of himself and was aware of his own physical limits:

If he were to feel like he needed to get off the field or stop what he was doing, he would just go up and say, he feels comfortable just going to the coach and saying "I need to stop."

The sibling's heart condition has been a part of the children's lives since early on. Most of the children have become very used to the daily influence it has on their lives and do not view it as being a negative experience. When asked what it is like to have a sibling with congenital heart condition, Owen explained: "There is nothing really wrong with that."

When answering the same questions, Aaron indicated that the best thing about having a sibling was having "someone to play with."

Despite the ongoing stress due to the chronic condition, the healthy children described a loving relationship with their siblings. When asked about the effect the

siblings' condition had on him and his family, Owen said: "We're just happy to even have her."

Most children spoke of the enormous support the siblings shared with each other, but also the normalcy of the sibling relationship compared to others'. Karen explained: "Well, we're just like every other brother – sister, or brother – brother, or sister – sister. We fight over stupid little things, but I think overall, it's a pretty close relationship...we're always there for each other."

Negative perceptions. Many of children interviewed were very honest and open about the negative aspects of having a sibling with congenital heart disease. Some children spoke of how difficult it is to deal with the illness. When asked about the impact on her and her family, Marie explained: "Sometimes more stressful because she won't do things and we ask her to do things and she doesn't want to admit to it, she's in denial about it, so it's frustrating."

Marie further elaborated on the difficulty of getting her sister to do things she needs to do:

Well, she won't wear her hearing aid and we tried to tell her and she would freak out and run upstairs because she thinks she's got the little kid syndrome where she thinks she can do whatever she wants and screams and makes attention tantrums and they still work because we don't want her to freak out.

When asked about the effect of his sibling's limitations, Owen said: "She can't handle it and I can't handle it, she gets frustrated...very easily...she gets mad and you can't understand what she is trying to say."

Some children felt more concern for their sibling and were worried about how their brother or sister felt. Joey indicated how sorry he felt for his sibling: “I feel sorry for him because he can’t play sports.”

The children were very aware of their sibling’s limitations, particularly with respect to sports and physical activity. Although the depth of each description varied, most children were able to explain what the experience is like, even if the explanation was very brief. When asked about what it is like to have a brother with congenital heart disease, Joey explained: “It’s okay, it’s a little bit scary.”

In addition to the daily impact of the illness, the families also had to make regular trips to the Vancouver Children’s hospital so that the siblings could undergo the regular check – ups and surgeries. The children had different views on what this experience was like for them. Although some children enjoyed the visits as they were able to miss school and visit family and friends, others did not view it as being so positive. Owen spoke of how boring the experience was:

I can remember how that feels. Like last year and the year before, three years ago, I can remember it was just so boring. I couldn’t believe how bored I was...I would like to come to see my sister, it’s just that I’m not very patient – I’m not that patient.

The parents also shared their perceptions of what the experience of regular trips to Vancouver was like for their healthy child. Aaron’s mother indicated that having to stay in Vancouver while leaving her son at home was difficult: “He really missed us. He was very clingy to me. I came home for a visit...I came home on Saturday, on the weekend for a quick visit and he was clingy and missed me...”

Throughout the discussions it became evident that the children demonstrated an enormous amount of care, concern, and love for their brother or sister. Having a chronic illness, however, requires an enormous amount of care and attention. As such, the question of whether the healthy children felt as though they were treated fairly by their parents was posed during the interviews. Many children agreed that their parents treated them fairly and that they were loved equally.

Perception of equal treatment. When asked whether both children do chores, most of the healthy children indicated that chores are shared equally and both siblings have responsibilities. Ben's mother further illustrated this by explaining: "We don't try to treat them any differently."

Some children, however, did not feel as though they were treated the same as their sibling. The children openly shared their experiences and were able to describe situations when they felt they were treated unfairly. When asked if he was treated any differently than his sister, Owen said: "A bit...sometimes she gets away with more...every time she does something wrong and gets away with it, mom just says it's because she's delayed."

When Karen was asked about whether she felt there are times when she is treated differently, she explained that she has felt that way and has even questioned her mom about it:

There are, I guess there are sometimes that I feel that way, but it's not an ongoing thing. I've asked her, I've said "who do you love more?" And she goes, "well I love you and (your sibling) both different ways, but exactly the same way." I think that's fine.

The children also spoke of age as influencing how they were treated. Marie spoke of being treated differently when younger. When asked if she felt as though she was treated any differently than her sibling, she explained: “Before...well, just because I think maybe she might be a little jealous of me because I’m getting more attention and now she’s starting to feel that way.”

Overall, when asked, most children agreed that they were treated with fairness, that they engaged in the same amount of chores, and that they were both loved equally. Through the discussions with the families, it appeared as though these children are being raised in supportive, loving environments with parents who understand and try to meet the needs of both their healthy children and the ill siblings. Although these are children in unique and challenging situations, they spoke of the strength and the importance of their relationship with their family. Despite how frustrating, scary, and difficult having a chronically ill sibling can sometimes be, the children in this investigation described how normal their sibling relationship was.

Theme Cluster 2: Impact on the Family

Because the children interviewed exist within a family, it was important to understand how they perceive their sibling’s congenital heart disease to affect not just them, but also their family as a whole. The children were asked to describe their experiences of how the illness affects the family and to share their perspectives of the daily impact congenital heart disease has on the lives of the family members. Throughout the discussions, the children provided insight into the ways in which the family had to adapt in order to accommodate the sibling’s illness, as well as their

perceptions of the limitations imposed upon the family as a result of their sibling's congenital heart disease and the consequent effects.

Adapting. Congenital heart disease has been a part of the children's lives for as long as they can remember. Adapting to their sibling's chronic condition has become a way of life for the healthy children and their families. Most parents indicated that their children have never experienced anything but the heart condition. When asked about how it affects her son, Joey's mother explained: "Well, he's grown up with it so it's been a part of our life."

Another mother answering the same question, put it simply by saying: "It's pretty normal."

At the time of data collection, the nearest paediatric cardiologist was in Vancouver. As a result, the families had to make regular trips to the Vancouver Children's Hospital. Many of the children shared what this experience was like for them. Some children were able to accompany their family on these trips while others stayed with relatives or friends.

Despite regular visits to Vancouver, some parents explained that congenital heart disease had little effect on the family. Karen's mother indicated there really was not much of an impact on the family: "Because it's not really in our faces all the time...other than travelling to Vancouver every couple of years..."

When Karen was asked about how the illness affects the family, she explained: "I don't really notice it that much because it's not like he has to take medicine for it or go see the doctor like everyday to see if everything's okay."

Karen elaborated further by saying: “I don’t know how (it affects the family) but it just, a tiny little bit. There might be little things but I don’t know what they are. A little bit, yeah.”

Perception of limitations. Having to adapt to a sibling’s chronic illness can be a challenging experience. Some of the children’s siblings with congenital heart disease required much medical attention and were very limited in their physical and mental abilities. As such, the experience of adapting to their sibling’s illness imposed limitations on their family’s daily life so as to ensure the health and well-being of the child.

When asked how congenital heart disease limits their family’s activities, most children were able to share the kinds of limitations their family had to accommodate. Owen shared his frustrations about having to accommodate his sibling’s behaviour when the family went out together: “I like going to the stores with her and my mom and my dad but she always screams.”

In addition to the child’s behaviour limiting the family’s activities, the health concerns of the child also contribute to family limitations. A child with congenital heart disease is more susceptible to getting sick and must be monitored closely when doing physical activities. All of the families interviewed were aware of the potential harm certain activities could cause the child with congenital heart disease as well as the importance of always being prepared in case of an emergency.

Owen’s mother spoke of the impact the child’s heart condition had on family outings: “We can’t as a family go for a major hike you know, we can’t take her

wherever. If she was a typical child without the heart defect we would be out hiking Thetis Lake.”

Joey’s mother spoke of similar precautions the family took while doing many things together: “We have to be careful where we go camping...not to go too far away in case of an emergency, make sure we have our cell phones and oxygen.”

Her son further explained: “(We) need our bikes to rush back home (in case of an emergency).”

The same family offered insight into the impact it had on socializing with friends: “We have friends and family that smoke; we don’t go to their houses, unfortunately.”

Karen explained how it felt always having to be extra careful: “Well, it’s sort of annoying because...if someone’s sick in his classroom, we always have to make sure he gets checked out for it like the next day.”

The parents interviewed spoke of the stress that was a part of their daily lives as they cared for their sick child. Marie’s mother shared how she behaved with her healthy child as a result of being chronically concerned and stressed out: “It hasn’t been quite as bad lately, but like you get really stressed out when her heart’s going too fast, or she gets sick, so we’re probably not as patient with Marie – always stressed out.”

Each family shared the experience of having a child with congenital heart disease. The experience involved adapting to the needs of the child and modifying their daily lives accordingly. For the healthy siblings, this involved limited family

activities as well as having to constantly be prepared for emergencies and being cautious at all times.

Theme Cluster 3: Impact on Sibling Relationship

One of the most valuable relationships in a child's life is that with their sibling. Sibling relationships provide the context for the development of social skills and friendship. Of all the relationships between family members, it is the sibling relationship that will last the longest (Stoneman & Brody, 1993). It was imperative to better understand the impact the child's heart condition had on the relationship between the healthy child and their sibling. Parents were asked to share their perspectives on their healthy child's relationship with their sibling. When the children shared their experiences, they discussed both the positive and negative impacts. As well, the age of the siblings emerged as a contributing influence on their relationship with one another.

Parental perceptions. When asked about their child's relationship with their sibling, all parents agreed that their children have a normal sibling relationship involving both fighting and caring deeply for each other. Aaron's mother described her children's relationship: "Most of the time, quite nice. They do get along, they play. But, just like any siblings they have their share of arguments and fights and whatnot..."

Karen's mother illustrated the same insight: "Oh yeah, they fight, they kick, they hit...pretty normal. When it comes down to the nitty gritty they are there for each other – they really do love each other."

Positive impact on relationship. When the children were asked to describe their relationship with their sibling, many of them also indicated that they had a close relationship and that they really loved each other. The following quotations illustrate the close relationship:

“We’re like a sibling relationship where we always do fight, but there are always times when we are always there for each other.” (Marie)

I think overall it’s a pretty close relationship, because if one of us was sad about something, our day was really, really horrible and we just don’t really want to do anything we just like, want to sit around doing nothing, or we’re crying, we’re both, we’re always there for each other...” (Karen)

Some children indicated they were just lucky to have someone to play with:

“We’re happy to even have her.” (Owen)

“I sleep with her.” (Aaron)

“We play Nintendo and bay blades together.” (Joey)

Negative impact of relationship. As with most sibling relationships, these children were able to describe some negative aspects of their relationship with each other. Some children felt as though their sibling got away with more. Karen indicated that her sibling didn’t always do his chores: “I’ll just do them because it makes me mad when he doesn’t do it.” Karen also felt as though her mom “sometimes loved her brother more.”

Many of the children were open about having disagreements with their sibling. Marie explained that her sister’s heart condition made her “very cranky and not always agreeable.”

Other children indicated that, like with many siblings, they don't always get along:

"Sometimes we fight." (Ben)

"We fight. We fight all the time." (Aaron)

"We get along kind of half and half." (Joey)

"Sometimes she's a pain and I don't want to deal with her." (Owen)

Impact of age on relationship. Many of the children described the experience of having a sibling as being like any other sibling relationship. They described getting along with their sibling as well as fighting with them at times. The child's heart condition did at times make some of the children feel as though their siblings got away with more. The heart condition, however, was not the only factor influencing the sibling relationship. Age too, was brought up many times, particularly by parents, as being a contributing factor to the relationship the siblings had with each other. As many parents indicated, puberty and becoming a teenager significantly impacted the relationship. Karen's mother explained:

She's 15, so she's starting to sort of get normal. Like it's starting to happen like this – she's done this peak, she's been at the very worst that they can be hormonally and then now she's starting to pull around in the peak, so that's where she is, and he's just starting and they, like right now, the clash in a big way. It's all hormonal and emotional, but they drive me absolutely insane. They've come down to being physical.

Many parents suggested their children had a much closer relationship than other brothers and sisters particularly when they were younger. However, the parents

indicated that as the children are getting older, the sibling relationship is changing. As a result of puberty, children want more privacy, space, etc. This was described as having a negative impact on the relationship. Owen's mother indicated, that because of her children's age difference, and her healthy child becoming a teenager, they are "starting to annoy each other." She further explained: "Up until about a year ago they were as close as you could imagine any kids being. In the past year it's (the relationship) changed, but up until that they lived and breathed for each other."

Ben's mother illustrated the same phenomenon:

I think that until recently they probably had a much better relationship than most brothers and sisters...it's kind of only been in the last year that they've started to have a few more arguments. She's starting to want to keep to herself.

As a result of having a brother or sister who requires constant care and attention, siblings may feel jealous. Again, age was a factor and was described as influencing the siblings' feelings of jealousy. Some children in the study indicated that when they were younger, they felt more jealous of their sibling. Marie stated that "she (sibling) got all of the attention" and although that is no longer the case, her relationship with her sibling is being affected by their ages: "We get along sometimes and she seems, but she's just like, I don't know, going through puberty or whatever, she's gotten more hormonal and less easy to be around."

For healthy and non-healthy children alike, the family plays an enormous role. The children interviewed shared their experiences and offered insight into what it is like to have a sibling with congenital heart disease. These children discussed how

their lives have been affected by their siblings' condition and openly shared both the positive negative aspects of being a child in family with a chronically ill sibling. Each child described their experiences and perceptions of how they, their families, and their relationship with their siblings are impacted by congenital heart disease. For some, the impact is great, for others it is less severe. For all, it appears to be a unique experience that has enabled the children to acquire coping skills, resiliency, and knowledge.

Category 2: Social Development

Children of all ages derive pleasure from socializing with peers. Furthermore, friendships not only provide a context for the development of social skills, but they also have an enormous impact on the overall quality of life for children. The children in this study attended school and spent their majority of their day interacting with peers. Due to their unique situation and the potential for teasing, understanding the social experiences of these children was imperative to the study.

The social development category contains three clusters: 1) Peer Acceptance, 2) Peer Awareness, and 3) Teasing. The themes which emerged from the data analysis are summarized in Table 4. They are then discussed and illustrated with quotations taken from the interviews.

Table 4
Social Development- Themes Within Each Cluster

Clusters		
Peer Acceptance	Peer Awareness	Teasing
Themes within each Cluster		
Parental Perceptions of Social Development (67%)	Knowledge and Understanding (50%)	Episodes of Teasing (50%)
Social Satisfaction (100%)		Absence of Teasing (83%)

Theme Cluster 1: Peer Acceptance

Understanding the social experiences of these children was valuable to the investigation. Parents were asked for their perception of their child's social development and satisfaction in addition to their child's perception, in order to observe any conflicting perspectives. Children described how satisfied they were with the number of friends they had and how accepted they felt by their peers.

Parental perceptions of social development. Children in unique situations, such as having a sibling with congenital heart disease, may be more vulnerable to teasing and social dissatisfaction. As all of the children interviewed spend the majority of their day at school with peers, it was important to better understand how the parents perceived their child's social development and experiences outside the home. Many parents indicated the importance of friends in their child's life. Fortunately, all parents described their children as having many friends and being very social. Karen's mother described her daughter as being "very social" with a variety of friends: "That's how she is, because I see her at school, she's got athletic friends, she's got weird friends..."

When asked about her child having friends, Aaron's mother explained: "He has lots of friends."

Ben's mother described the importance of communicating with and receiving feedback from her child's teacher. Through communicating with the teacher, she was better able to understand her child's social development and experiences with classmates. She explained how her son is viewed at school: "His teachers always call him the peacemaker."

Some parents spoke about the child's group of friends and how they react to both the child and the sibling. While discussing her son's peers, Owen's mother explained how accepting they were of his sibling: "He's got a couple of friends from school and they are really good with (his sibling) as well. They really accept her."

Social satisfaction. The children, too, described themselves as having many friends and as feeling accepted by their peers. When asked, all of the children indicated that they were happy with the number of friends they had and felt socially satisfied and accepted. Karen explained: "I have lots of friends. I have like good friends, I have friends, and I have people I talk to on chat lines or something and that are in my class." The same child illustrated how accepted she felt by her peers and how important it was for her to always be herself and to not succumb to peer pressure: "I'm not going to be like, "well, do you want me to do my hair like that?" Or "do I really have to curl my hair every morning just to be with those kids?"

The following statements taken from three children illustrate how satisfied they were with their friends and how accepted they felt:

"They are just fine with who I am." (Ben)

“Like everyone who knows me in school like always says, “oh your sister is so cute.” (Owen)

“I have lots of friends at school. No, I don’t act differently around them.”
(Aaron)

When asked about their friends and peer acceptance, all of the children described having positive social experiences. Fortunately, all of the children interviewed felt accepted by their peers and were socially content. The parents, too, were very much aware of their child’s social development and their perceptions were in agreement with those of their children.

Theme Cluster 2: Peer Awareness

Knowledge and understanding. The question of whether or not peers were aware of their sibling’s heart conditions was posed to the children. Most of the children explained that their friends either had no idea that the sibling had a heart condition or if they did know, they were not bothered by it at all. When asked whether her friends know about her brother’s congenital heart disease, Karen explained that when her friends found out, they were very surprised:

Well, he doesn’t act any different, why not? I said, “Because it’s not humongous, it’s not like everyone needs to know, he doesn’t like people knowing.” But, most people do know – but after I tell them once, they don’t even think about it so they forget.

Karen’s mother indicated that the reason for this was that “it’s not in their face all the time. It’s so invisible.”

As with many chronic illnesses, the severity of congenital heart disease varies with each child. For some, the heart condition is less visible and less severe. These children may look, act, and play like any other child. As such, people are very surprised when they are informed of the illness. One child explained that her sibling's illness goes unnoticed by friends: "Because he plays sports, he runs, he goes out with his friends. You wouldn't even think he had it because he goes and plays soccer until he's so tired like every other kid."

Marie illustrated this concept further by indicating that her friends "don't really know that much about her condition, like her hearing."

According to her mother, this was because "looking at her you can't tell."

The child explained: "It's when they see her scar."

Sometimes, the children's friends are curious and are comfortable asking questions. When Aaron was asked whether his friends knew anything about his sibling's condition, he indicated: "They've asked me about it and they've done nice things."

The children interviewed provided positive feedback about their experiences with their friends. The children indicated that they were comfortable sharing information if their peers were interested in knowing about their sibling. For the most part, however, the peers did not notice the sibling's heart condition. This was due to the fact that unless the scar was shown, it was deemed an invisible illness.

Theme Cluster 3: Teasing

Given the unique situation the participating children were in due to their siblings' chronic illness, and because they spend the majority of their day with

classmates, the children may have been more vulnerable to being teased. In order to better understand the social experiences of the children, it was important to question whether or not the children were teased because of their sibling. Furthermore, parents were included in order to provide insight about what they had seen or heard regarding episodes of teasing, both past and present.

Episodes of teasing. When children were asked if they were ever teased by other children, most of them stated they were not. Parents, however, had a different view. Some of the parents indicated that there was a time when the child was teased because of their sibling. After posing the question to the child, Owen's mother explained:

That happened when you were in grade one, a boy teased you about your sister. It was grade one. He got teased and boy was he upset. Other than that he's only had one incident at school where somebody's made a comment.

When Ben's mother was asked if she had ever witnessed an episode of teasing, she indicated that she could recall an occasion, but only vaguely remembered: "Yeah, I'm recalling something about that, I can't remember what it was...yeah, it's not a common occurrence."

Marie did indicate that her peers made fun of her sibling. She explained that, although most of her friends do not know about the heart condition, they laugh at her sibling's behaviour. The following quote taken from the interview illustrates this experience: "They don't really know that much about her condition like her hearing, when she would say things to people they would think that was funny."

When asked if she felt bothered by it, the child stated: “People at this age are just immature and you can’t really do anything about it.”

Although the child suggested her friends do not know much about the condition, she further explained that eventually, they figure it out: “People know eventually. Like my friend, says like “why is she going insane?”

When she was asked how she handles it, she simply explained: “What can you say? Problem somebody is born with.”

Absence of teasing. The majority of the participating children indicated that they had many good friends who were accepting of them. Moreover, five out of the six participants stated that they were never teased by other people. Sometimes the answers were brief: “No, I’m never teased,” while other children, along with their parents, elaborated further.

Karen indicated that there was never any teasing because “no one ever knows.”

Joey stated that he was not teased either, but his mom explained that this was because everyone knew: “School wise and people wise, we always let everyone know in case of an emergency. School’s been there and child life specialist’s been there, so everybody’s just sort of grown up with him.”

When asked whether they had witnessed any teasing, both Aaron and his mother stated, “No, it’s been very good that way.”

Feeling socially satisfied is extremely important to children, particularly those who may be at a greater risk for teasing and loneliness. Central to this investigation was developing a better understanding of the personal experiences of the participating

children, including social development. Fortunately for all, themes of social satisfaction, happiness, and feelings of acceptance emerged.

Category 3: Well-Being

When a child has to cope with a sibling's chronic illness, their overall sense of well-being and quality of life may be affected. It was important that the study give voice to the participating children in order to develop a better understanding of and give meaning to their personal experiences associated with their quality of life.

The children's' discussion about their well-being included sharing information about their overall wellness. Their focus on well-being centered around worry, both parental perceptions and their own, the benefits associated with having a sibling with congenital heart disease, and describing an overall awareness of the condition and its impact.

The well-being category consists of three clusters: 1) Worry, 2) Benefits, and 3) Awareness. The thematic structure derived from the interview data is arranged within each cluster and is depicted in Table 4. Additionally, the themes are further discussed and include quotations taken from the interviews as a way to enhance the meaning of the lived experience.

Table 4
Well-Being – Themes Within Each Cluster

Clusters		
Worry	Benefits	Awareness
Themes within each Cluster		
Parental Perceptions of Worry (100%)	Travel and Exposure (50%)	Parental Perceptions (100%)
Awareness of Parental Concern (100%)	Access to Family and Friends (83%)	Knowledge of Impact of Illness (100%)
Focus of Child's Worry (100%)		Lack of Awareness (67%)
		Awareness of Limitations (100%)
		Involvement (83%)

Theme Cluster 1: Worry

Congenital heart disease is a serious chronic illness that can be fatal. The surgeries, the need for constant care, and the importance of always being prepared for an emergency can be scary for many children and cause an enormous amount of worry within the family. Shedding light on the anxiety and concern that these children felt each day was important to the study in order to better understand their lived experience.

During the interviews, parents were asked to share their perceptions about their child's worry. Additionally, children discussed their awareness of what they thought their parents worried about. Because each experience for these children is different, the focus of the child's worry also emerged as a theme.

Parental perceptions of worry. When asked, all parents indicated they worried a lot about their sick child's health and well-being. Some parents even shared a fear

that their child may die. The majority of the parents interviewed indicated that they perceive their healthy child to be aware of their constant concern and stress that comes with having a chronically ill child.

When discussing what her child worries about, Karen's mother stated: "I think she worries about how he feels, just like how he gets tired and I think it's little things."

She further illustrated her awareness of her child's concern and her influence on her child's worrying:

I think that sometimes Karen tends to worry, and so it's if she suspects that I'm worried about something, she gets, you can tell, she's stressed. She's always worried about her little brother because...she's been a part of this whole, you know, when we first found out he was, we were going to have him, she's been totally a part of it – his whole life. And she's also been a caregiver...

After confirming that her child was aware that she worries, Joey's mother turned to her son and said: "You don't want anything to happen to him, do you?"

Not all parents wanted their children to know of their worries. Some felt that the less the children knew, the better. When asked about whether her children are aware of her worrying, Ben's mother explained that it's best not to worry her children: "Don't want to worry them about things they don't have to worry about. There's nothing major to worry about anyway."

Marie's mom indicated that she knew her child was aware that she worried because she was "always stressed out" worrying about her child's health.

When asked about his child worrying, Marie's father explained that the child worried more when younger:

Well she was worried about it when she was little. She was worried about what the doctors were doing to her in Vancouver which was one of the reasons I came home – to take care of her when she was at my parents'.

When Aaron indicated that he thought his parents only worried a little bit, his mom explained that they worry more than he may be aware:

Our worries are more with, on top of the pacemaker, she's got congested heart failure. The pacemaker is doing its job, it's done, it's finished. But, now it's trying to clear up all the congestion. So that's the worry right now. All the drugs she's on, trying to clear that up.

When asked, parents were very aware of what they worried about in front of their children. Some parents indicated that they openly shared their concerns with their children while others seemed to shelter their children by keeping many of their worries to themselves.

Awareness of parental concern. When the children were asked whether their parents worried, the majority were very aware of their parents worry. While some answered briefly with "yes, I know they worry," others provided more elaborated discussions. Karen described how her mom confirms her worries with her:

At the soccer game a couple of days ago, he was on the side and I was sitting beside my mom and she starts looking at (sibling) and she goes, "is he okay?" Because there is only sometimes she gets a little bit worried.

The same child explained how aware she was of her mom worrying:

I know when she's worried. She won't even tell me and just the way she'll look at him or she'll look at someone and talk about it. She might not be really worried, but there are times when she just...she won't even say anything, she'll just look at me in a funny way...she'll go "what's wrong?" She's too much like me.

Additionally, many of the children interviewed were aware of the sorts of things their parents worried about. When asked what she thinks her mom worried about, Karen indicated "his health."

Aaron shared his knowledge of his sibling's pacemaker and the associated worry. When asked what his parents worried about, he stated: "(They worry) about the pacemaker. Whether it's working or not working."

Ben spoke of knowing that his parents worry about "the heart problem."

Owen further describe the additional concern about having to give his sibling her medication: "They worry about her health. The major thing they worry about is forgetting to give her Coumadin. I know they worry about that."

Owen was able to demonstrate his understanding of his mom's behaviour when she was upset or concerned. When the child's mother asked what she did when she worried, the child illustrated his awareness by stating: "Cry sometimes."

Owen also spoke of his parents worrying about his relationship with his sibling when he was younger: "When I was younger I definitely know that they worried about me that I was so attached to my sister. They were worried it was going to affect me through the years, but it didn't."

Ben indicated that he was not aware that his parents worried. This was reassuring to his mom as she stated she has “lots of worries” but did not want to worry her child.

When asked what her parents worried about, Marie illustrated how much her parents worried about her sibling’s well – being at school:

(If) she doesn’t come home, how she does in school because she doesn’t want to seem like her friends get A’s, so she tries even harder to get good grades and sometimes she can’t and you can’t help her because she’s unhelpable...and the way people treat her at school, she can’t hear properly.

Many of the children interviewed demonstrated an awareness of what their parents worried about. Of particular interest to the investigation, was the focus of the child’s own worry so as to gain a better understanding of what the children worried about.

Focus of child’s worry. Karen explained how she worries about it everyday: “Yeah, I worry about it everyday because when we went to the doctor, we found out what is actually was...”

While some children are less worried than others, some show more fear when understanding the illness. When Joey was asked how his sibling’s heart problem made him feel, he responded with: “It’s scary.”

Ben stated that having a sibling with congenital heart disease “is weird” but indicated he didn’t worry about her.

Aaron indicated that he “feels sad” and worries a lot about his sibling.

Some children spoke of how their worries have changed now that they are older. Owen explained that he used to worry she was “going to get hurt or something” but no longer worries about that.

The children and parents interviewed shared their personal experience of the constant worry that filters into their daily lives. Both the children and their parents demonstrated an awareness of each other’s concern and were knowledgeable about the focus of each other’s worry.

Theme Cluster 2: Benefits

Despite the constant worry associated with having a sibling with congenital heart disease, many of the children shared the positive aspects that were part of their daily lives as a result of having a chronically ill sibling. Children discussed the benefits of going to Vancouver as well as being able to visit family and friends.

Travel and exposure. When asked about the advantages of having a sibling with congenital heart disease, many children indicated that “going to Vancouver” was a benefit.

Karen explained that she goes to Vancouver so she will not miss anything, but she also stated: “I get to visit people that are in Vancouver and it gives me a break.”

Joey indicated that he gets to visit his “funny friend” at the hospital. His mom further explained: “He’s made good friend with the echo-tech, they are really pretty good buds.”

Some parents indicated that the advantages for their healthy children included easing their fears as well as being more comfortable around hospitals:

The fact that her brother's had these problems and she's dealt with those over the years; going to hospitals, having blood tests, and watching him get all of this stuff done, I think it's helped her because she's much more calm...I think seeing him be calm over his stuff has helped her... (Karen's mother)

Marie's mother indicated that the exposure to people with various challenges has impacted her healthy child in a positive way: "(She is) more comfortable around mentally challenged people, so it was a good experience."

Access to family and friends. In addition to being exposed to the hospital and being able to make special trips to Vancouver, many children explained that visiting family and friends was also a benefit.

While some children visited family and friends in Vancouver, some were able to stay at friends' homes while their parents travelled.

Aaron spoke of his experience of staying his grandparents: "They always give me treats."

Being able to describe positive aspects of having a sibling with congenital heart disease was important to these children. While there is much worry and ongoing concern, the children still have things that they can look forward to. Some children spoke of wanting to travel to Vancouver so as to remain aware of the process.

Theme Cluster 3: Awareness

Awareness is another aspect of well-being that emerged throughout the interviews. The discussion around awareness focused on parental perceptions of how aware they felt their healthy children were of the illness, children's knowledge of the

impact of the illness, in some cases, a lack of awareness, an awareness of the perceived limitations, and the degree of involvement.

Parental perceptions. Some parents felt their children were fully aware of the illness, while others explained that their children did not know a lot about their sibling's condition. Many indicated the reason for this was that they had never fully explained the complexities of congenital heart disease.

When asked whether or not her healthy child knows about her sibling's heart condition, Karen's mother explained: "She knows what is wrong and why it's wrong." She further explained the importance of her daughter understanding:

Well I can always explain it to her so that she can understand it and we tried to explain it to her so that she knows that right now, he's okay, and when he's not okay, then she'll know that, too.

When asked about how much her child knows of the illness, Joey's mother explained:

Well, he's grown up with it so it's been a part of our life...he knows and looks out for the (symptoms as well)...And so he's always looked out for him. He sees his face get red and stuff. He's the brother that says. "you should take a break, your face is red."

Owen's mother indicated that she hasn't explained a lot to her child: "He's never asked me questions...he's always just been concerned."

Ben's's mother explained that her child may not be fully aware of his sibling's heart condition:

She's not really severe. I don't think Ben understands what her heart condition is all about. Like her surgery was when she was a baby...he has some idea that there's something going on, but I don't think he's really aware of the extent...

A quotation from Aaron's mother is used to further illustrate this point:

To be honest, I probably really haven't explained it to him. We dealt with it and he knows that she's had operations when she was a baby, and as he describes it, she almost died, and he knows that part. The details of what the exact problem is, he doesn't know. He sees us giving her medications everyday, the rush before school, and giving medications just before rushing for the bus.

While some parents described having fully explained the illness to their children, some parents indicated that they had not shared much information with their healthy children. Despite this, most of the children interviewed were fairly knowledgeable about the impact and effect the illness had on their sibling.

Knowledge of impact of illness. Karen was able to demonstrate her overall knowledge about heart conditions: "Every kid's different. There might be some kids who get sick every day and never go to school because something's wrong."

Joey was able to describe his sibling's heart condition: "He has a stent...it's shaped like a bar and they put it in. The heart goes on a different side."

He also demonstrated an awareness of the impact on his sibling: "He has to get surgeries and stuff...he gets tired and has to have oxygen."

Owen indicated his awareness of the impact congenital heart disease had on his sibling: “She gets blood tests and stuff and surgeries...she’s delayed in learning.”

Additional quotations from the interviews illustrate the participant’s awareness of the effect on their siblings:

“One of her vocal chords is paralyzed...she can’t speak very well.” (Ben)

“She’s very cranky...has a leaky valve” (Marie)

“It’s sad because she has to keep the pacemaker in for the rest of her life.”

(Aaron)

“At school, she used to always feel sick.” (Marie)

Although the children were able to describe some of the impacts the condition had on their sibling, not all of the children were very aware of the illness.

Lack of awareness. When asked if she was aware of any effects the illness had on the family, Karen indicated that: “There might be little things but I don’t know what they are.”

Owen indicated that he “didn’t know much” about his sibling’s congenital heart disease and explained he didn’t understand it when he was younger.

When Aaron was asked what he knew about his sibling’s heart condition, he responded with “well, nothing really,” and was unable to explain why his sibling went to the hospital or got sick.

Awareness of limitations. While some children were unable to explain a thorough impact or understanding of the illness, all of the children were aware of the limitations instilled upon their sibling as a result of having congenital heart disease.

The physical limitations and the need for always looking out for their sibling are a constant reminder of their sibling's illness.

Karen was able to fully describe the symptoms associated with her sibling's fatigue: "He sort of gets tired like in soccer, most kids get red of course, his cheeks won't go red, but around his face and a little bit on his nose it will go red."

She further explained: "He sometimes gets tired, there are times that he gets sick easily."

The following quotations taken from the interviews illustrate the participant's awareness of their siblings' limitations:

"He gets tired and he has to have oxygen." (Joey)

"He plays T-Ball and he could do that but he can't play soccer and stuff."
(Joey)

"She gets frustrated easily." (Marie)

"Sometimes you have to let her do things, like clean her room sometimes, she needs more of a break than I do." (Owen)

"She goes quite slow and keeps her bike to the side of the road."

"Her heart beats too fast, she can't play a lot of sports. Takes a pill everyday."
(Marie)

"She broke her arm on the swing set, so like everything, she can't even go to the dentist without getting antibiotics." (Marie)

"She can't go near magnets and she can't go on the monkey bars." (Aaron)

Involvement. In addition to being aware of the limitations congenital heart disease had on their siblings, many children spoke of being very involved in their

sibling's lives. Involvement included attending medical appointments, making other people aware in case of an emergency, and knowing about their sibling's heart condition.

Karen's mother spoke of how important it was to her child that she attends her sibling's doctor's appointments:

They've been each other's support for a very long time, so she goes to all of the appointments. If he has a doctor's appointment, a specialist's appointment, she wants to be there...because then she can ask questions, she gets sort of the straight goods so that she knows.

Karen explained: "Well I don't want to miss anything and know that something else has gone wrong, or he's doing something wrong."

Karen went on to describe how important it was to know everything in case something ever happened to her mom: "I would rather know than not know about it, because say, my mom wasn't there and something happened, I'd know what to do...and I wouldn't want to be in a spot where I didn't know what to do."

Joey's mother spoke of the importance of being open with her children with respect to their sibling's heart condition: "We are pretty open with them about the whole thing, so if there's a concern, they know. We don't like to keep it a secret from them."

Joey's mother illustrated the importance of having family and friends involved and aware: "...We've always let everybody know in case of an emergency. Everybody's just sort of grown up with him."

While some parents are adamant on keeping their children involved, some prefer to share only a little bit of the information. Ben's mother stated: "I probably haven't explained it to him...the details of the exact problem, he doesn't know."

Parents feel they know what is best for their child. What they decide to tell them and how involved they would like their children to be, is a personal choice. All of the parents interviewed spoke of doing what they felt is best for their children.

Having a sibling with congenital heart disease has been a part of these children's lives since day one. Despite the constant fears, worries, and concerns, all of the children interviewed appeared to be happy, to be supported by their family and friends, and to be enjoying life.

Recommendations

At the end of each interview, families were asked to offer advice to other healthy siblings and families with a child who had congenital heart disease. The majority of the children interviewed shared a positive experience of having a sibling with a heart condition. Some, however, had a less positive experience. It was important that their voices be heard so that other families may benefit from their experiences and suggestions. All together, 13 recommendations were offered. Listed below are all of the (paraphrased) recommendations from both the healthy siblings and the parents:

Children Recommendations

1. Children should try not to worry a lot.
2. Just be happy to have a sibling.
3. It is important to be prepared to care for the sibling.

4. Children advise other children to gain as much knowledge as they can about their sibling's illness.
5. Some children stress the importance of being involved with the sibling's medical care and need. Try to attend as many medical appointments as possible so that you always know what's going on.
6. Knowledge is very important. Make sure you know and understand the symptoms that you should be looking out for.
7. In order to stay involved and knowledgeable, ask as many questions to parents and doctors as possible.
8. Sometimes your sibling may be frustrating or mean, but in order to stay happy and positive, do not take anything personally.

Parent Recommendations

1. Parents advise kids to speak up and to look out for their sibling.
2. Parents advise other parents to do what is best for their kids.
3. Try to keep the congenital heart disease as low a profile as possible, so as to treat the child like a normal sibling.
4. Parents advise other parents and children to be patient with the sibling.
5. It is important to treat the ill sibling as a normal child so that they wouldn't feel funny about having something wrong.

Summary

Chapter four presented the analysed data. First, the essential structure of experience was outlined. Second, the major categories and thematic structure that resulted from the data were illustrated. The clusters and themes that were derived

from each category were also examined. Personal quotations taken from the interviews were included throughout in order to enhance and to give meaning to the participants' lived experience. Finally, the recommendations offered by the participants to other families were presented.

Chapter five will discuss the study findings in the context of extant literature, the limitations of the study, the implications for families, educators, and medical professionals, and the implications for future research.

Chapter 5 – Discussion

Introduction

Chapter five is organized into four parts. The first section provides a summary of the study results. These findings are discussed in the context of the goals of the research presented in the introduction to the study. The results are further discussed in the context of related literature. In the second part of the chapter, the limitations of the investigation are examined. The third part explores the implications of the study findings. The chapter concludes with directions for future research.

Summary of Results

Guided by phenomenology, this study investigated the experiences of healthy siblings who have a brother or sister with congenital heart disease. The study examined the perceptions of the healthy siblings as well as the parents' perceptions of what the experience was like for their healthy child.

Semi-structured interviews were used to elicit information about the participants' lived experiences. Using a thematic analysis procedure, the researcher examined the interviews for themes and patterns of experience.

Research Contributions

Purpose 1: To gain a better understanding of how a child's congenital heart disease affects siblings.

The healthy siblings have been exposed to congenital heart disease and its effects for most of their lives. As such, when asked what it is like to have a sibling with congenital heart disease, most children described it as being a normal experience. Congenital heart disease, however, did influence the healthy children in

many ways. The participants spoke of the need to look out for their sibling and to ensure his or her safety at all times. The children also described how they have to cater to their sibling's needs by being aware of potentially harmful situations and having to limit what the family can and cannot do, accordingly.

All of the children and parents interviewed described being in a close, supportive family. The children spoke of the enormous amount of care and concern they felt for their sibling on a regular basis. Despite the birth order and age difference between the siblings, all of the children described the importance of looking out for their brother or sister. The age and gender of the healthy sibling did not seem to influence their experience with congenital heart disease. This finding is in contrast, however, to the research done by Breslau et al. (1981) who indicate that:

Birth order was found to have a statistically significant interactive effect with sex: among siblings younger than the disabled children male siblings had greater impairment than female siblings, whereas among siblings older than the disabled children female siblings were psychologically worse off (p. 350).

As their siblings are at a greater risk of physical exhaustion and illness, the children spoke of having to be very knowledgeable about the kinds of situations their families must avoid so as to prevent injury or harm. This involved having to limit what the family can and cannot do as well as having to be very aware of the symptoms and behaviours that may be a cause for concern. According to Taylor, Fuggle, and Charman (2001), "well siblings' perceptions and attitudes (about the chronic physical condition and its impact on their lives) are associated with adjustment" (p. 959). This may account for the healthy siblings' overall ability to

cope and to accept the condition. Although most children were aware of their sibling's abilities and limitations, not all of them were fully aware of the effects of the condition. This appeared to be a result of the parents feeling that the less the children knew the better.

The amount of concern and attention given to their siblings did create feelings of jealousy among some of the healthy children. This is consistent with the observations of Berkobien (2002) who states that when parents are continually consumed with their ill child, the healthy children may react with jealousy and anger. However, Berkobien also indicates that such reactions result in resentment toward the ill child. This was not evident in the current investigation as most children spoke of love and support for their siblings. Despite the occasional occurrence of jealousy, however, all of the participants felt that they were generally treated fairly and had the same amount of household responsibilities as their siblings.

Feeling as though they were treated the same as their sibling had a positive impact on the healthy child's relationship with their sibling. The children described their relationship as being like any relationship between siblings. Although they were close, they also spoke of having their fair share of fights. Thus, congenital heart disease did not appear to have a negative impact on the relationship between the siblings.

With regular trips to Vancouver as a result of their sibling's condition, many children spoke of the benefits associated with such excursions. Not only were they able to visit family and friends, but they also became exposed to other children with disabilities and illness. This is consistent with the work of Janus and Goldberg (1995)

who suggest that siblings with a chronically ill brother or sister are more capable of empathy, sensitivity, and an awareness of other's suffering.

Purpose 2: To identify the daily stressors and challenges these siblings face.

Fortunately, the healthy children in the present study did not view their sibling's heart condition as being an overly burdensome experience. These children come from very supportive families where communication and openness is encouraged. Gordon et al. (1996) indicate that these variables, among others, such as the nature and extent of the illness and the resources made available to the family all contribute to the healthy sibling's overall well-being and response to the illness and the associated effects.

Despite the children's sense of well-being and acceptance of the condition, the healthy siblings did speak of the daily worry that went along with having a sibling with congenital heart disease. Part of this worry came from an awareness of their parents' worry.

Related literature (Gordon et al., 1996; Wong, 1999; Knafl & Zoeller, 2000; Burke et al., 2001; Streisand et al., 2001) describes the challenges of raising a child with chronic illness and indicates that parents are under an enormous amount of stress and fatigue associated with the constant worrying. In the present study, such parental stress did have an effect on the healthy children. Some of the children described feeling more worried when they knew their parents were worried, and others described being very aware of when their parents were worried and how they expressed that behaviour. Some parents demonstrated stress and concern through crying and others confirmed their worries by discussing them with their healthy child.

When asked how congenital heart disease made them feel, all of the children spoke of being concerned and worried. Although the severity of the heart condition varied significantly from child to child, many of the healthy children described feeling scared, sad, and sorry for their sibling. These feelings are reflected in recent related literature. For example, the NRCRCCS (2002) suggests that most healthy siblings are left feeling worried and as a result, even angry with their brother or sister for having a chronic illness. Berkobien (2002) also indicates that some children may feel guilty for not having the condition. Although the children did not describe feelings of guilt per se, some children spoke of feeling sorry for their siblings due to their various limitations. The majority of the children spoke of their sibling's restrictions in relation to sports. The healthy children were very aware of what their sibling could and could not do and illustrated empathy towards such limitations.

Such empathetic behaviour among healthy siblings has been examined in previous literature. Research done by Janus and Goldberg (1995) illustrates the impact a healthy child's empathy has on the sibling relationship. Although further investigation is warranted, the scholars and their research illustrate a connection between a healthy child's empathetic abilities and the ill sibling's perception of their behaviour toward him or her.

In addition to the chronic daily worry and the limitations instilled upon them as a result of the heart condition, the children described having to always be prepared for an emergency and the importance of constantly being aware of the symptoms to look out for. While some of the children did not view this as being a negative experience, others described the constant preparations, adaptations, and extra

precautions to be annoying and frustrating. This difference in experiences and perspectives is consistent with the work of Wong (1999) who indicates that many studies have shown inconsistent findings regarding the experience of healthy siblings. Some siblings describe the experience as being normal or positive while other siblings have a more challenging experience and may be at a greater risk for maladjustment.

Overall, the results of the present investigation illustrate that the children and their families are coping effectively with the illness and the associated limitations. Additionally, despite the daily management of the illness, the healthy siblings do not view congenital heart disease as having a negative influence on their lives.

Purpose 3: To identify the experience of the siblings from the perspective of the parents.

Past research (Dyson, 19956; Knafl & Zoeller, 2000; Taylor et al., 2001) has examined parental perceptions about their healthy child's experience with having a sibling with chronic illness. The results of the research indicate that there are inconsistencies regarding the agreement between what the parents think the experience is like for their healthy child versus how the children themselves describe it to be.

In the current study, the families spoke of being open and communicative with each other. As a result, the parents were very aware of what the experiences were like for their healthy children. The parents and healthy children were in agreement when it came to discussing what the child knew about the illness, how the illness influenced the family, and the necessary precautions associated with the illness. This concept

may account for the healthy child's apparent resiliency and overall adjustment. This is consistent with the work of Taylor et al. (2001) who suggest that "parental awareness of the well siblings' perceptions and attitudes" (p. 960) is an important resiliency factor in healthy children.

The findings of this study also illustrate how concerned the parents were about their healthy child's well-being. The parents spoke of the chronic care and attention that their ill child required and the subsequent concern they felt that their healthy child was feeling left out. This is reflected in the work of Dyson (1996) whose research indicates that many parents of children with disabilities report feelings of guilt due to having to spend so much time with their child with the disability. In the present study, these feelings were not shared by the healthy children as they indicated that they did not feel left out. In contrast, however, the work by Knafl and Zoeller (2000) indicate that the parents in their study view the child's illness as having very little impact on the family.

The parents and healthy children also held shared views on their social development. Parents were very aware of their healthy child's friends, how socially satisfied they were, and whether or not the friends knew anything about the heart condition. Additionally, both the healthy children and parents agreed that teasing was not taking place. A few parents did, however, recall earlier episodes of the healthy child being teased because of their sibling. The children had no memory of such events.

Furthermore, the parents' and healthy children's perceptions of the sibling relationship were also in concordance with each other. Both agreed that they got

along as most siblings do, but also had the occasional fight like all siblings.

Additionally, the parents' perception that age was influencing the sibling relationship was shared with the healthy children. Some described their sibling as being more hormonal, cranky, and as wanting more space as they were becoming teenagers.

The overall findings of this study indicate that the healthy siblings are managing their sibling's illness and are coping effectively. Fortunately, and even surprisingly, their general sense of well-being and their overall quality of life have not been negatively affected. These children are, however, living in unique and often extraordinary circumstances in which they are expected to take on adult-like responsibilities as they care for, worry about, and cater to the needs of their sick sibling.

Limitations of the Investigation

As with most research, there were limitations in the present investigation. One of the limitations of the study was that it was limited to only six siblings and their parent(s), all of whom reside on Vancouver Island, British Columbia. A more varied sample representing a larger proportion of the population would have provided more depth to the data and stronger results.

Additionally, the research relied primarily on maternal reports as only two of the fathers were present during the interviews. Hearing from more fathers about their perceptions would have certainly enriched that data and may have provided different experiences than those shared by the mothers.

Furthermore, each participant who was interviewed came from middle class, Caucasian families. This may be non-representative of many other families who have

undergone similar experiences. It would have been valuable to select participants from various cultures and backgrounds in order to develop a better understanding of how such variables may influence the experience.

Another limitation of the study was that only siblings of children with congenital heart disease were investigated. Therefore, it is not possible to understand the experience of siblings in the context of any other chronic illness. Given the vast array of chronic paediatric conditions, it would be interesting and valuable to further our understanding of how other chronic illnesses, in addition to congenital heart disease, affect the lives of healthy siblings.

An additional limitation of the study was the age of the participants. The investigation was limited to children between the ages of seven and fifteen. As a result, it was difficult to get a lot of thorough information from the younger children, who were for the most part, quite shy. In some case, the parents even helped the child out by prompting them or answering for them. This certainly influenced the information received and the explanations and descriptions that the children were able to provide.

A final limitation of the study was that it was limited to the use of family-centered interviews. Although family-centered interviews enable the researcher to obtain multiple perspectives of the experience, thereby deepening the understanding, it does have its limitations. Children who are being interviewed along with their parents may feel as though they have to censor the sorts of things they share so as not to upset or offend their parents. Without parents present, however, children may have more freedom to disclose personal feelings and truthful information about their

experiences without worrying about their parents' reactions. All of the families in the present study chose to be interviewed together. As a result, the information received from the children may not be as representative of the lived experience had they been interviewed individually.

Although the intention of qualitative research is not to generalize to larger populations, the findings of this study may reflect the experiences of other children in similar situations. As such, some implications from the findings are offered for consideration.

Implications of the Findings

The major implications following the findings relate primarily to children, parents, and medical professionals. The interview themes have implications that ensure the experience of having a sibling with congenital heart disease is as positive and as manageable as possible.

The first implication is that information must be made available to healthy siblings so that they can better understand the condition. Findings of this study relate to previous literature about the effectiveness of the healthy child's involvement with and understanding of the chronic illness. Additionally, it is understood that families function as a whole and work together as a unit. As such, each member is affected to some degree by the child's congenital heart disease. Thus, the needs of all family members must be acknowledged and catered to. The children in the current investigation emphasized the importance and the desire to be involved in their sibling's care and to be knowledgeable about emergencies and precautions. As a result, medical professionals need to be aware that healthy siblings also require

information about their brother or sister's heart condition and should be provided with age appropriate literature. When it comes to managing a child's illness, it must be done with a family-centered approach so that all members are included and acknowledged.

Another implication is that parents also must have resources made available to help them communicate with their healthy children about their other child's illness. Fortunately, in the present study, the parents were seemingly well-educated and communicative with their children, and had various support systems within reach. For many other families, however, this may not be the case. Some families may not have similar financial resources, knowledge, or support available to them. For such families, it is vital that information on how to communicate with and involve the healthy siblings is provided. It was this open communication, inclusion, and awareness that appeared to be a major factor in the healthy siblings' resiliency in the present study. As a result, parents must be able to talk to the children in ways that help them to understand the illness and its effects and to be able to provide for a safe environment where children can share their anxieties and fears.

Directions for Future Research

There are several possible directions for future research that emerged from this investigation. First, it would be valuable to conduct a larger study that examines the same question so that a deeper understanding and stronger results would be achieved. By conducting such large scale research, variables such as age, gender, and culture may emerge as having an influence on the lived experience. The results may then lead to specific recommendations that meet the needs of individual families.

Many of the siblings from the present study spoke of the numerous worries and concerns they had about their brother or sister with congenital heart disease. Although they described being able to discuss their worries with their parents, they did not discuss being able to talk to other children in similar situations or being able to meet other healthy siblings of children with congenital heart disease. It would be interesting to evaluate the role and even the availability of sibling support groups as a place where children can communicate with others and share their anxieties and fears.

In addition to communicating with other children at sibling support groups, it is hoped that the children from the present study will be able to share their recommendations and experiences with other healthy siblings. This may be done by including their recommendations and advice in a school handbook developed by the researcher and the researcher's supervisor.

Another possible direction of the study would be to conduct a large scale, longitudinal study. Children with congenital heart disease are now living much longer due to medical advances. As a result, these children may undergo more surgeries and hospitalizations. Their initial surgeries took place either before their siblings were born, or when they may have been too young to remember. As reflected in the present study, the healthy siblings are old enough to be very informed and aware of the seriousness of the condition and of the ramifications of surgeries and potential complications. A longitudinal inquiry could examine the worries and fears the healthy children experience over time as a result of being aware of the reality of the condition and of seeing their sibling undergo medical procedures. The study could additionally

provide information on how the experience influences the healthy child's behaviour, relationship with the sibling and parents, and his or her experiences at school.

A final direction for future research would be to compare and to contrast the experience of healthy children of siblings with other chronic conditions. The present study only examines congenital heart disease, which affects a small percentage of the population. There are many other chronic paediatric disorders that influence the lives of siblings and their families. It would be beneficial to explore the common themes associated with having a sibling with chronic illness as well as to examine how unique each experience may be as a result of the various implications of different conditions.

Final Summary

This qualitative study provides an overview of what it is like to have a brother or sister with congenital heart disease. It is only an initial step in understanding the experience, but it does shed light on what these children go through on a regular basis.

This inquiry highlights the challenges and the stress the children and their families experience as a result of congenital heart disease. The children spoke of the chronic concern they had for their sibling as well as the consequent limitations instilled upon their families. In their own words, they opened the door into their world and offered a glimpse of what their lived experience was like.

The study also illustrated the parents' perceptions of what the experience was like for their healthy child. Fortunately, the parents were very aware of and in tune with the needs of their children. They understood what their children were going

through and the associated influences it had on their lives. They offered insights into their own lives and spoke of the very real fears and concerns they had for both the healthy child and the child with congenital heart disease.

Of note was the enormous amount of love and support the healthy children felt for their sibling. Despite the daily concern and implications of the illness, the children cared deeply about the health and well-being of their brother or sister.

The discussions with the children also highlighted their significant degree of resiliency and their coping skills. They are normal children in extraordinary circumstances and yet, they are content, well-adjusted, individuals who, along with their siblings, are making the most of their childhood.

This study has provided an initial understanding of the experience of children of siblings with congenital heart disease. Further research is warranted in order to develop a deeper understanding of the experience and to provide specific implications for both theory and practice.

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Appendix A: Ethics Approval Certificate

University of Victoria - Human Research Ethics Committee***Certificate of Approval***

<u>Principal Investigator</u> Tara Elliott Graduate Student <u>Co-Investigator(s):</u>	<u>Department/School</u> EPLS	<u>Supervisor</u> Dr. Jillian Roberts	
<u>Title:</u> Experiences of Siblings of Children with Congenital Heart Disease			
<u>Project No.</u> 400-02	<u>Approval Date</u> 22-Nov-02	<u>Start Date</u> 22-Nov-02	<u>End Date</u> 21-Nov-03

Certification

This is to certify that the University of Victoria Ethics Review Committee on Research and other Activities Involving Human Subjects has examined the research proposal and concludes that, in all respects, the proposed research meets appropriate standards of ethics as outlined by the University of Victoria Research Regulations Involving Human Subjects.

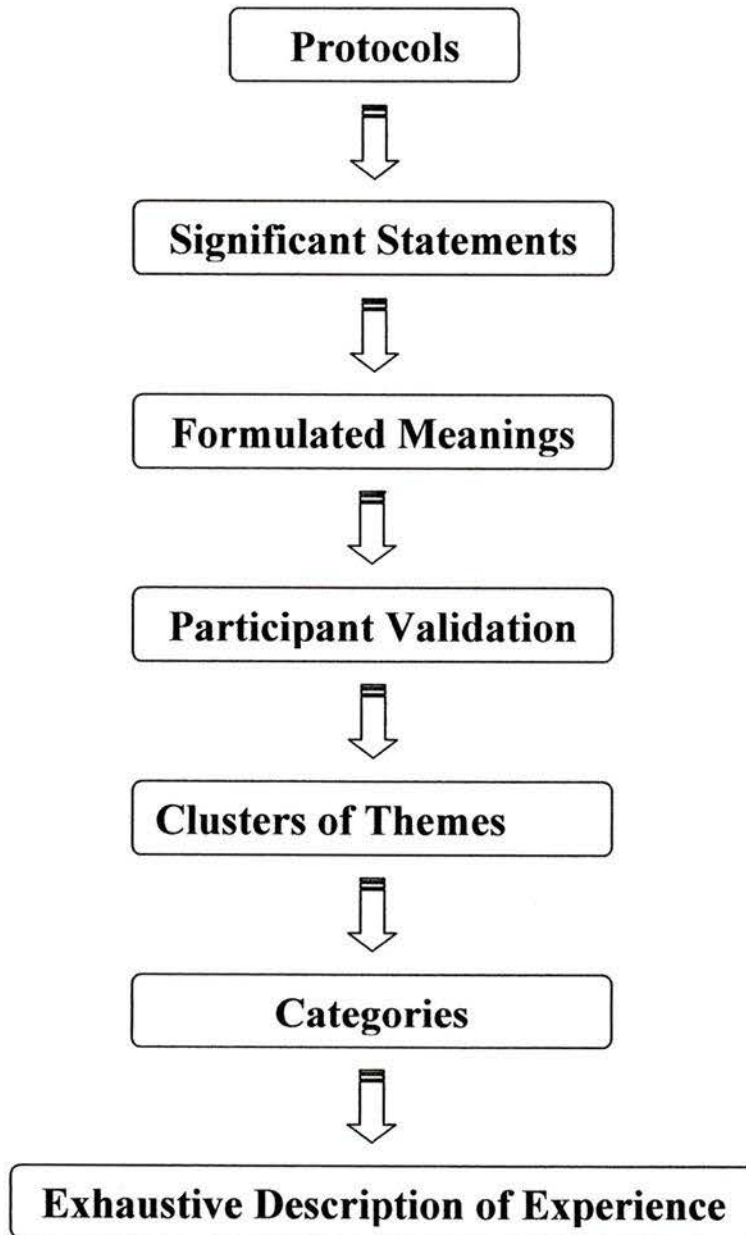


J. Howard Brunt
Associate Vice-President, Research

This Certificate of Approval is valid for the above term provided there is no change in the procedures. Extensions/minor amendments may be granted upon receipt of "Request for Continuing Review or Amendment of an Approved Project" form.

Appendix B: Data Analysis Procedure

Data Analysis Procedure



Appendix C: Consent Form for Parents

UNIVERSITY OF VICTORIA
OFFICE OF THE VICE-PRESIDENT, RESEARCH
HUMAN RESEARCH ETHICS COMMITTEE

The Experiences of Siblings of Children with Congenital Heart Disease

You are being invited to participate in a study entitled “The Experiences of Siblings of Children with Congenital Heart Disease” that is being conducted by Tara Elliott. Tara Elliott is a graduate student in the department of Educational Psychology and Leadership Studies at the University of Victoria and you may contact her if you have further questions by calling (250) 381-0837.

As a graduate student, I am required to conduct research as part of the requirements for a degree in Educational Psychology. It is being conducted under the supervision of Dr. Jillian Roberts. You may contact my supervisor at (250) 721-7817 or via email at jjrobert@uvic.ca.

The purpose of this research project is to gain a better understanding of the experiences of siblings of children with Congenital Heart Disease. Specifically, the main objectives are:

- 1) To better understand how a child’s chronic illness affects siblings,
- 2) To identify the daily stressors and challenges these siblings face and
- 3) To identify the siblings’ and families’ experience from the parents’ perspective

Research of this type is important because there has been very little recent research that addresses the experience of siblings. Literature to date, however, does suggest that siblings of a child with chronic illness are often overlooked, and yet, are affected in numerous ways. However, explorations of childhood chronic illness have rarely considered the quality of relationships of healthy siblings. Given the significance of sibling relationships, any changes in the health or well-being of one sibling will affect the healthy sibling(s) and may cause disruptions in family functioning.

It is hoped that this research will provide insight into the experience of siblings in order to improve the quality of life of families. It will also enable health professionals to better understand the needs of the siblings and thereby provide more adequate, age-related information to the siblings to help them understand the illness and treatment. Insight will also help families to develop coping mechanisms that will be beneficial to family health.

You are being asked to participate in this study because you are a sibling in a family where a child has congenital heart disease. We would like to learn from your experience so that we can help health professionals develop adequate programs to meet your needs. Hearing your thoughts and experiences will be valuable for this investigation.

If you agree to voluntarily participate in this research, your participation will involve two interviews lasting approximately 1- 2 hours. The interviews will be tape recorded and later transcribed. The first interview will involve having you describe your experiences of having a chronically ill sibling. The second will be a follow-up interview that will enable you to review and confirm the themes highlighted from the first interview.

Participation in this study may cause some inconvenience to you, including having to allocate your time to be interviewed. You may also have to express certain feelings including anger

and sadness. You will never be forced to remain in the study or discuss negative experiences if you choose not to. The interviews will be paced according to your needs and desires. Although these interviews are not expected to be distressing, the researcher and the researcher's supervisor have arranged for Dr. Galia Artzy (Victoria psychologist) to be available to participants for free counseling follow-up if needed.

The potential benefits of your participation in this research include informing health care professionals about the experiences of siblings of children with chronic illness. Life is forever changed for a family when they have a child with a chronic illness. The uncertainty, fears and sudden changes can be a source of great stress for a family. Increased survival rates in children afflicted with heart disease have created an environment where all family members must adapt to stressful and persistent conditions. Given the inconclusiveness in research, it is necessary to develop a more thorough understanding of how healthy siblings are affected by their brother or sister's illness. Developing a more comprehensive understanding of these children's experiences will advance our knowledge of how these families cope and function. This information will be vital for professionals who are working to improve the quality of life for these families.

Your participation in this research must be completely voluntary. If you do decide to participate, you may withdraw at any time without any consequences or any explanation. If you do withdraw from the study your data will not be included in the final analysis. Please understand that there is to be no researcher or parental pressure to participate. In addition, you may refuse to participate or withdraw from the study at any time without consequence.

In terms of protecting your anonymity, your identity will never be revealed. No names will be attached to the data; only a code number will be used.

Your confidentiality and the confidentiality of the data will be protected by keeping all data in a locked cabinet and destroyed after five years. Taped interviews will be burned and written information will be shredded.

Other planned uses of this data include using it as a way to direct the implementation of family support programs to be used by health professionals. In addition to sharing the findings with the academic community, the results of this research will also be presented at conferences and published in academic journals. In addition, it is expected that these findings will lay the foundation for doctoral studies.

It is anticipated that the results of this study will be shared with others in the following ways: I will share the findings with families who participated.

In addition to being able to contact the researcher and the supervisor at the above phone numbers, you may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Associate Vice-President, Research at the University of Victoria (250-472-4362).

Your signature below indicates that you understand the above conditions of participation in this study and that you have had the opportunity to have your questions answered by the researchers.

Name of Participant

Signature

Date

A copy of this consent will be left with you, and a copy will be taken by the researcher.

Appendix D: Interview Guide for Children

I invite you to share with me the experiences of having a brother or sister with congenital heart disease. I am interested in knowing what it is like to be in a family where a child has a chronic illness. I am going to ask you some questions about you and your family. What you share with me will help prepare other children and families to live with a brother or sister who has congenital heart disease. Please let me know if the questions do not make sense, as I will happily reword them.

What is it like to have a brother or sister with congenital heart disease?

*Knowledge of Illness

- 1) Do you know why your brother/sister goes to the hospital/gets sick?
- 2) What can you tell me about your brother/sister's disease?
- 3) What is congenital heart disease? How does it affect your brother/sister?

*Sibling Relationships

- 1) Can you describe your relationship with your brother/sister? Do you get along with each other? Are you close? Tell me more.
- 2) Are there things that your brother/sister cannot do that you can? (Like what?) What is that like for you?

*Impact on Family

- 1) How do you think your brother/sister's illness affects the family?
- 2) What do you think your parent's worry about?

*Impact on Siblings

- 1) What do you have to do because of your brother/sister's illness? How do you help? Do you have special chores? How do you feel about that?
- 2) Are you treated differently than your brother/sister? How so? How does that make you feel?

*Social Belonging

- 1) Do you have many friends at school? Do you feel accepted by your friends?

- 2) Do people ever tease you about your brother/sister's illness? What is that like for you?

***Benefits of having an ill sibling**

- 1) Can you describe any good things about having a sick brother/sister? Tell me more.
- 2) What advice would you give to other children who have a brother/sister with congenital heart disease?

Appendix E: Interview Guide for Parents

I invite you to share with me your child's experience of having a sibling with congenital heart disease. I am interested in knowing what it is like to be in a family where a child has a chronic illness. I am going to ask you some questions from your perspective about the experience of your healthy child. What you share with me will help prepare other children and families to live with a brother or sister who has congenital heart disease. Please let me know if the questions do not make sense, as I will happily reword them.

What do you think it is like for your son/daughter to have a brother or sister with congenital heart disease?

*Knowledge of Illness

- 1) Does your son/daughter know why his/her brother/sister goes to the hospital/gets sick?
- 2) What do you think he/ she would tell me about your son/daughter's disease?
- 3) What do you think he/she would say congenital heart disease is? How would he/she describe how it affects your son/daughter?

*Sibling Relationships

- 1) How would you describe their sibling relationship? Do they get along with each other? Are they close? Tell me more.
- 2) Are there things that he/she doesn't do that your healthy child can? What do you think that's like for your healthy child?

*Impact on Family

- 1) How do you think your healthy son/daughter describes the effects the illness has on the family?
- 2) What do you think he/she thinks you (and your spouse) worry about?

*Impact on Siblings

- 1) What does your son/daughter have to do because of the brother/sister's illness? How does he/she help? Does he/she have special chores? How do you think he/she feels about that?
- 2) Do you feel that your son/daughter thinks he/she is treated differently than your child with congenital heart disease? How so? How do you think that makes

him/her feel?

***Social Belonging**

- 1) Does your son/daughter have many friends at school? Do you think he/she feels accepted by their friends?
- 2) Do people ever tease your son/daughter about their brother/sister's illness? What is that like for them?

***Benefits of having an ill sibling**

- 1) Can you describe any good things you think he/she would say about having a sick brother/sister? Tell me more.
- 2) What advice do you think he/she would give to other children who have a brother/sister with congenital heart disease?

Appendix F: Analysis Confirmation Letter to Participants

Date

Address

Dear _____,

I hope this letter finds you all happy and healthy. Enclosed you will find the transcribed interview. To date the transcribed interview has been initially analyzed to identify themes. Please notice that all names have been removed to ensure confidentiality and anonymity.

At this point in the study, I would ask that you both:

- 1) Read through the typed transcription for accuracy.
- 2) Read the handwritten notes in the margins to see that they reflect appropriate themes for what you were describing at the time.

I will be contacting you by telephone in one week to follow-up on the interview. Thank you very much for your time and energy with this research study. If you have further questions please do not hesitate to call me at (250)381-0837 or email taraellio@hotmail.com.

Sincerely,

Tara Elliott
Researcher

Enclosure (1)

VITA

Surname: Elliott

Given Names: Tara Louise

Place of Birth: Regina, Saskatchewan, Canada

Educational Institutions Attended:

University of Victoria	2001 to 2003
University of Victoria	1995 to 2000

Degrees Awarded:

B.Ed	University of Victoria	2000
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Honours and Awards:

N/A

Publications:

N/A

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Title of Thesis:

The Experiences of Siblings of Children with Congenital Heart Disease

Author



Tara Louise Elliott

September 5, 2003